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ABSTRACT

The document contains transcripts of the Congressional hearings on the Developmental Disabilities Act Amendments of 1978 (H.R. 11764), legislation designed to improve and coordinate provision of services to the developmentally disabled. Presented along with the text of H.R. 11764 are the texts of H.R. 278, H.R. 2151, and H.R. 10059 (all part of the Autistic Children Research Act). Statements from the following individuals are among those give (affiliation in parentheses): Mary S. Akerley (past president, National Association for Autistic Children); Roy V. Bruninghaus (executive director, North Carolina Council on Developmental Disabilities); Robert R. Humphreys (commissioner, Rehabilitation Services Administration); Norman V. Lourie (chairman, National Task Force on Developmental Disabilities); Richard Schiefelbusch (American Association of University Affiliated Programs for the Mentally Disabled); and Richard E. Verville (counsel, National Easter Seal Society for Crippled Children and Adults). Also provided are additional materials which include a summary of service network plan year objectives and associated implementation activities; national projections of the total number of developmentally disabled to be served for fiscal year 1978; "Being Disabled in America" (a concept paper by R. Humphreys; and a statement submitted by the National Association of Private Residential Facilities for the Mentally Retarded. (SBH)

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DEVELOPMENTAL DISABILITIES ACT AMENDMENTS OF 1978

U S DEPARTMENT OF HEALTH.
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HEARINGS

BEFORE THE

SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT

OF THE

COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE HOUSE OF REPRESENTATIVES

NINETY-FIFTH CONGRESS

SECOND SESSION

ON

H.R. 11764

A BILL TO AMEND THE DEVELOPMENTAL DISABILITIES SERVICES AND FACILITIES CONSTRUCTION ACT TO REVISE AND EXTEND THE PROGRAMS UNDER THAT ACT, AND FOR OTHER PURPOSES

H.R. 278, H.R. 2151, and H.R. 10059

BILLS TO PROVIDE FOR ACCELERATED RESEARCH AND DEVELOPMENT IN THE CARE AND TREATMENT OF AUTISTIC CHILDREN, AND FOR OTHER PURPOSES

APRIL 4 AND 5, 1978

Serial No. 95–103

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- National Association of State Mental Health Program Directors:
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  - Schnibbe, Harry, executive director.
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- National Task Force on Developmental Disabilities:
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- Osteogenesis Imperfecta, National Capital Area, Margaret Cauffield, coordinator.
- Tuberos Sclerosis Association of America, Linda G. Connors, codirector.
- United Cerebral Palsy Associations, Inc., Elsie D. Helsel, Ph. D., chairperson, governmental activities.

DEVELOPMENTAL DISABILITIES ACT AMENDMENTS OF 1978

TUESDAY, APRIL 4, 1978

House of Representatives,
Subcommittee on Health and the Environment,
Committee on Interstate and Foreign Commerce,
Washington, D.C.

The subcommittee met, pursuant to notice, at 10 a.m., in room 2322, Rayburn House Office Building, Hon. Paul G. Rogers, chairman, presiding.

Mr. Rogers. The subcommittee will come to order please.

Today we open hearings on legislation to extend and amend the program for the developmentally disabled. Some 10 million of our citizens suffer from disabilities incurred during the developmental years. For at least 2 million of these individuals, their handicap is a severe one.

Although they often require and can benefit from support and services from many existing education, medical and service programs, too often the needs of the developmentally disabled are overlooked or inadequately addressed.

The program established by the Developmental Disabilities Act was designed to provide funds to support activities at the State level to identify persons in need and to develop plans for serving the developmentally disabled population, as well as to provide moneys to develop model programs, to gain access to existing programs which can provide services and to fill the gaps between those programs so that the developmentally disabled can be effectively served.

One important effect of this program has been to enlist a number of advocates and interested persons who are willing to work diligently in the States to make the needs of the developmentally disabled actually known and a source of concern.

As we address extension of this legislation this year, we will be particularly interested in receiving the advice and counsel of our many witnesses on two particular issues: whether a change in the definition of what constitutes a developmental disability should be made and whether the particular needs of the developmentally disabled continue to require the focus of a program designed particularly for them, rather than for all severely disabled persons.

We certainly welcome the witnesses today, Dr. Carter, do you have a statement too?

Mr. Carter. Thank you, Mr. Chairman.

I am pleased to join you and other subcommittee members in holding these hearings on amendments to the developmental disabilities program.

The purpose of this program is to improve and coordinate the provision of services to persons with developmental disabilities, who are persons with significant handicaps which impair their ability to function normally in society. Frequently we find that these individuals fall through the cracks of various programs which could help serve their needs.

In other instances the necessary programs or services are simply not available. Some of the people who fall through the cracks over the years have been dyslectics.

Mr. Chairman, as we recall, in the 93d Congress the word "dyslexia" was included in the definition of developmentally disabled. I am interested to see what steps this particular department has made in covering dyslectic children. As you know, Mr. Chairman, the dyslectics have difficulty in learning to read and as a result, as children, they become frustrated and many of them drop out of school.

Later they often come into conflict with the law. Approximately 10 percent of our prison population at the present time is composed of dyslectics. This is an area to which we have not given sufficient emphasis and I hope, Mr. Chairman, in this legislation we will give further consideration and backing to the care and training, particularly training, of the dyslectics.

Thank you, Mr. Chairman.

Mr. Rogers. Mr. Ottinger.

Mr. Ottinger. Mr. Chairman, I too share your interest and Dr. Carter's interest in this program. I am somewhat concerned as to the limitations of definitions of those people who are included, particularly the age limit of 22. I understand that cerebral palsy and other debilitating diseases can make themselves known to people after that age cutoff and still present the same kind of problems to the individual.

The other problem is the definition apparently excludes multiple sclerosis and a number of other diseases that do cause the same problems to individuals as those that are covered.

I, therefore, think we should either consider broadening the definition or consider the legislation that has been introduced in the Senate by Senator Randolph which would eliminate this program and in effect have a much broader coverage and also much larger sums involved.

Mr. Rogers. Thank you.

Without objection, the text of H.R. 11764, H.R. 278, H.R. 2151, and H.R. 10059 will be printed at this point in the record.

[Testimony resumes on p. 44.]

[The text of the bills referred to follows:]

95TH CONGRESS
2D SESSION

H. R. 11764

IN THE HOUSE OF REPRESENTATIVES

MARCH 22, 1978

Mr. ROGERS (for himself and Mr. CARTER) introduced the following bill; which was referred to the Committee on Interstate and Foreign Commerce

---

A BILL

To amend the Developmental Disabilities Services and Facilities Construction Act to revise and extend the programs under that Act, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SHORT TITLE; REFERENCE TO ACT

SECTION 1. (a) This Act may be cited as the "Developmental Disabilities Act Amendments of 1978".

(b) Except as otherwise specifically provided in this Act, whenever in this Act an amendment or repeal is expressed in terms of an amendment to, or repeal of, a section or other provision, the reference shall be considered to be made to a section or other provision of the Developmental Disabilities Services and Facilities Construction Act.

SHORT TITLE; FINDINGS AND PURPOSES

SEC. 2. Part A is amended by striking out section 10 and inserting in lieu thereof the following sections:

"SHORT TITLE

"SEC. 100. This title may be cited as the 'Developmental Disabilities Act'.

"FINDINGS AND PURPOSES

"SEC. 101. (a) The Congress finds that—

"(1) there are more than two million persons with developmental disabilities in the United States;

"(2) individuals with disabilities occurring during their developmental period are more vulnerable and less able to reach an independent level of existence than individuals who have a normal developmental period on which to draw during the rehabilitation process;

"(3) persons with developmental disabilities often require specialized services to be provided from birth to death and by many agencies in a coordinated manner in order to meet the persons' needs;

"(4) general service agencies and agencies providing specialized services to disabled persons tend to overlook or exclude persons with developmental disabilities in their planning and delivery of services;

"(5) it is in the national interest to strengthen specific programs, especially programs that reduce or eliminate the need for institutional care, to meet the needs of persons with developmental disabilities; and

"(6) there is a need for a national plan for persons with developmental disabilities which takes into account the needs common to the entire developmentally disabled population as well as those needs unique to each identifiable group in the population.

"(b) (1) It is the overall purpose of this title to assist States to assure that persons with developmental disabilities receive the care, treatment, and other services necessary to enable them to achieve their maximum potential through a system which coordinates, monitors, and evaluates those services and which ensures the legal and human rights of persons with developmental disabilities.

"(2) The specific purposes of this title are—

"(A) to assist in the provision of services to persons with developmental disabilities, with priority to those persons whose needs cannot be comprehensively covered or otherwise met under the Education of All Handi-

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capped Children Act, the Rehabilitation Act of 1973, or other health, education, or welfare programs;

"(B) to develop a national plan for meeting the identified and unmet needs of persons with developmental disabilities, which plan is coordinated with State plans relating to persons with developmental disabilities;

"(C) to assist States in appropriate planning activities;

"(D) to make grants to States and public and private, nonprofit agencies, in accordance with specified national priorities, to establish model programs, to demonstrate innovative habilitation techniques, and to train professional and paraprofessional personnel;

"(E) to make grants to university affiliated programs to assist them in administering, operating, planning, and developing demonstration programs for the provision of services to persons with developmental disabilities, and interdisciplinary training programs for personnel needed to provide specialized services for these persons; and

"(F) to make grants to support a system in each State to protect the legal and human rights of all persons with developmental disabilities without regard to age or eligibility for services funded under this title.".

DEFINITIONS

Sec. 3. (a) Section 102 (1) is amended by inserting "the Northern Mariana Islands," after "Guam,".

(b) Section 102 (8) is amended—

(1) by inserting "(A)" after "(8)";

(2) by striking out "means specialized services" and all that follows through "such term includes" and inserting in lieu thereof the following: "means priority services (as defined in subparagraph (B)), and any other specialized services or special adaptations of generic services for persons with developmental disabilities, including in these services the"; and

(3) by adding at the end thereof the following new subparagraphs:

"(B) The term 'priority services' means individual client management services (as defined in subparagraph (C)), infant development services (as defined in subparagraph (D)), alternative community living arrangement services (as defined in subparagraph (E)), and nonvocational social-developmental services (as defined in subparagraph (F)).

"(C) The term 'individual client management services' means such services to persons with developmental disabilities as will assist them in gaining access to needed social,

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medical, educational, and other services; and such term includes—

"(i) follow-along services which insure, through a continuing relationship (lifelong if necessary) between an agency or provider and a person with a developmental disability and his family, that the changing needs of the person and the family are recognized and appropriately met; and

"(ii) client coordination services which provide to persons with developmental disabilities support, access to (and coordination of) other services, information on programs and services, and monitoring of the person's progress.

"(D) The term 'infant development services' means such services as will assist in the prevention, identification, and alleviation of developmental disabilities in infants, and includes (i) early intervention services, (ii) counseling and training of parents, (iii) early identification of developmental disabilities, and (iv) diagnosis and evaluation of such developmental disabilities.

"(E) The term 'alternative community living arrangement services' means such services as will assist persons with developmental disabilities in maintaining suitable residential arrangements in the community, and includes in-house services (such as personal aides and attendants and other domestic assistance and supportive services), family support services, foster care services, group living services, respite care, and staff training, placement, and maintenance services.

"(F) The term 'nonvocational social-developmental services' means such services as will assist persons with developmental disabilities who are over eighteen years of age in performing daily living and work activities.".

(c) Section 102 is amended by amending paragraph (9) to read as follows:

"(9) The term 'State Planning Council' means a State Planning Council established under section 137.".

(d) Paragraph (10) of section 102 is amended to read as follows:

"(10) The term 'university affiliated program' means a program which is operated by a public or nonprofit entity, which is associated with (or is an integral part of) a college or university, and which provides for at least the following activities:

"(A) Interdisciplinary training for personnel concerned with developmental disabilities and related handicapping conditions.

"(B) Provision of exemplary services relating to persons with developmental disabilities and related handicapping conditions.

1C

"(C) Technical assistance and consultation for State and local public agencies, private agencies, service providers, State Planning Councils, protection and advocacy systems (described in section 113), and other similar entities.

"(D) (i) Dissemination of research findings, relevant to services provided to persons with developmental disabilities, to entities described in subparagraph (C), (ii) providing researchers and government agencies sponsoring such research with information on the needs for further service-related research, and (iii) conducting selected service-related research.".

NATIONAL ADVISORY COUNCIL ON SERVICES, FACILITIES, AND RIGHTS OF THE DEVELOPMENTALLY DISABLED

SEC. 4. (a) Paragraph (1) of section 108 (a) is amended to read as follows:

"(1) (A) There is established a National Advisory Council on Services, Facilities, and Rights of the Developmentally Disabled (hereinafter in this section referred to as the 'Council'). The Council shall consist of—

"(i) sixteen ex officio members, described in subparagraph (B); and

"(ii) twenty members appointed, in accordance with subparagraph (C) and without regard to the provisions of title 5, United States Code, governing appointments in the competitive service, by the Secretary from persons (I) who are advocates in the field of services to persons with developmental disabilities (including leaders in State or local government, in institutions of higher education, and in organizations which have demonstrated advocacy on behalf of such persons), and (II) who are not full-time employees of the United States.

"(B) The ex officio members (referred to in subparagraph (A)(i)) shall be of twelve representatives from the Department of Health, Education, and Welfare, two representatives from the Department of Labor, one representative from the Department of Housing and Urban Development, and one representative from the Department of Transportation, each such representative to be designated by the Secretary of the respective Department.

"(C) Of the appointed members (referred to in subparagraph (A)(ii))—

"(i) eight shall be persons with developmental disabilities or with a milder form of any such disability;

(ii) seven shall be immediate relatives or guardians of persons with mentally impairing developmental disabilities, at least one of whom is an immediate relative or guardian of an institutionalized person with a developmental disability;

"(iii) one shall be the director of a protection and advocacy system (described in section 113) for developmentally disabled persons;

"(iv) one shall be the staff director of a State Planning Council (established under section 137); and

"(v) three shall be selected from State and local direct service providers (both public and private) and university affiliated programs.".

(b) Section 108(a)(3) is amended by striking out "twice" and inserting in lieu thereof "three times".

(c) Section 108(b) is amended—

(1) by inserting "office" after "shall hold", and

(2) by striking out "has expired" and inserting in lieu thereof "have expired".

(d) Subsection (c) of section 108 is amended to read as follows:

"(c) The Council shall—

"(1) develop a national five-year plan for persons with developmental disabilities, which plan identifies the unmet service needs of persons with developmental disabilities and the actual and potential infringements of the legal and human rights of these persons;

"(2) annually review and revise this five-year plan;

"(3) recommend to the Secretary priorities (consistent with the priority of the services described in section 102(8)(B)) for special projects authorized under part D of this title;

"(4) advise the Secretary with respect to any regulations promulgated or proposed for promulgation by the Secretary in the implementation of the provisions of this title;

"(5) monitor the execution of this title and report directly to the Secretary on any delay in the rapid execution of this title; and

"(6) submit to the Congress anaually a report on the Council's activities under this subsection during the year and on any needs and priorities relating to persons with developmental disabilities not being met under this title.".

(e) Subsection (d) of section 108 is amended to read as follows:

"(d) The Secretary shall make available to the Council at least one full-time professional staff person and one full-time secretarial assistant, such other secretarial, clerical, and other assistance, such statistical and other pertinent data prepared by or available to the Department of Health, Education, and Welfare, and such other resources as the Council may require to carry out its functions.".

(f) The heading to section 108 is amended by striking out "SERVICES AND FACILITIES FOR" and inserting in lieu thereof "SERVICES, FACILITIES, AND RIGHTS OF".

(g) (1) Section 110(a) is amended by striking out "Services and Facilities for" and inserting in lieu thereof "Services, Facilities, and Rights of".

(2) Subsections (a) and (e) of section 145 are amended by striking out "after consultation with the National Advisory Council on Services and Facilities to the Developmentally Disabled" and inserting in lieu thereof "taking into consideration the priorities established by the National Advisory Council on Services, Facilities, and Rights of the Developmentally Disabled".

(h) Notwithstanding the amendment made by subsection (a) of this section, the appointed members of the National Advisory Council on Services and Facilities for the Developmentally Disabled (as established under section 108(a) of the Developmental Disabilities Services and Facilities Act as in effect before the date of the enactment of this Act) shall be considered appointed members of the National Advisory Council on Services, Facilities, and Rights of the Developmentally Disabled (as established under the amendment made by subsection (a) of this section) until their terms (as of the date of the enactment of this Act) expire or such members resign from their office.

REGULATIONS

SEC. 5. The text of section 109 is amended to read as follows:

"SEC. 109. The Secretary, not later than one hundred and eighty days after the date of enactment of any Act amending the provisions of this title, shall promulgate such regulations as may be required for the implementation of such amendments.".

EVALUATION SYSTEM

SEC. 6. (a) Section 110 (a) is amended—

(1) by striking out "within two years of" and all that follows through "Bill of Rights Act develop" in the first sentence and inserting in lieu thereof "develop, not later than October 1, 1979,";

(2) by striking out "Within six months after the development of such a system, the" in the second sentence and inserting in lieu thereof "The";

(3) by striking out "the receipt of assistance under this title, that each State" in the second sentence and inserting in lieu thereof "a State's receipt of assistance on and after October 1, 1980, under this title, that the State";

(4) by striking out "Within two years after the date of the development of such a system, the" in the third sentence and inserting in lieu thereof "The"; and

(5) by striking out "the receipt of assistance under this title, that each State" in the third sentence and inserting in lieu thereof "a State's receipt of assistance on and after October 1, 1982, under this title, that the State".

(b) Subsection (c) of section 110 is amended to read as follows:

"(c) Upon development of the evaluation system described in subsection (b), the Secretary shall submit to Congress a report on the system, which report shall include an estimate of the costs to the Federal Government and the States of developing and implementing such a system.".

(c) Section 110 is amended by striking out subsection (d).

RIGHTS OF THE DEVELOPMENTALLY DISABLED

SEC. 7. Section 111 is amended by adding at the end thereof the following new sentence:

"The rights of persons with developmental disabilities described in findings made in this section are in addition to any constitutional or other rights otherwise afforded to all persons.".

PROTECTION AND ADVOCACY OF INDIVIDUAL RIGHTS

SEC. 8 (a) Section 113 (a) is amended—

(1) by striking out "The Secretary shall require",

and all that follows through "such system will (A)" and inserting in lieu thereof "In order for a State to receive an allotment under part C, (1) the State must have in effect a system to protect and advocate the rights of persons with developmental disabilities, and (2) such system must (A)"; and

(2) by striking out the last sentence thereof.

(b) The second sentence of section 113(b)(1) is amended to read as follows: "Allotments and reallotments of such sums shall be made on the same basis as the allotments and reallotments are made under the first sentence of subsections (a)(1) and (d) of section 132, except that no State in any fiscal year shall be alloted an amount which is less than the greater of $50,000 or the amount of the allotment to the State for the previous fiscal year.".

(c) Paragraph (2) of section 113(b) is amended to read as follows:

"(2) For allotments under paragraph (1), there are authorized to be appropriated $9,000,000 for the fiscal year ending September 30, 1979, $12,000,000 for the fiscal year ending September 30, 1980, and $15,000,000 for the fiscal year ending September 30, 1981.".

GRANT AUTHORITY, APPLICATIONS, AND AUTHORIZATION OF APPROPRIATIONS FOR UNIVERSITY AFFILIATED PROGRAMS

SEC. 9. (a) Part B is amended to read as follows:

"PART B—UNIVERSITY AFFILIATED PROGRAMS

"GRANT AUTHORITY

"SEC. 121. (a) From appropriations under section 123, the Secretary shall make grants to university affiliated programs to assist in the planning, development, administration, operation, and maintenance of the activities described in section 102(10), and of such additional activities as the Secretary determines to be appropriate to carry out the purposes of this title.

"(b) The Secretary may make a grant to a university affiliated programs receiving a grant under subsection (a) to support one or more of the following activities:

"(1) Affiliation of the program with governmental and nonprofit organizations, in order to promote the provision of quality services to persons with developmental disabilities who reside in geographical areas where adequate services are not available.

"(2) Expansion of the program so it can assess the need for trained personnel in providing assistance to persons with developmental disabilities or with related handicapping conditions.

"(3) Provision of service-related training to practitioners providing services to persons with developmental disabilities or with related handicapping conditions.

"(4) Conducting a long-term applied research program which can develop methods for applying basic research findings to produce more efficient and effective methods (A) for the delivery of services to persons with developmental disabilities or with related handicapping conditions, and (B) for the training of professionals, para-professionals, and parents who provide these services.

"APPLICATIONS

"SEC. 122. (a) Not later than one year after the date of the enactment of the Developmental Disabilities Act Amendments of 1978, the Secretary shall establish standards for university affiliated programs. These standards for programs shall reflect the special needs of persons with developmental disabilities or with related handicapping conditions who are of various ages, and shall include performance standards relating to each of the activities described in section 102 (10).

"(b) No grant may be made under section 121 unless an application therefor is submitted to, and approved by, the Secretary. Such an application shall be submitted in such form and manner, and contain such information, as the Secretary may require. Such an application shall be approved by the Secretary only if the application contains or is supported by reasonable assurances that—

"(1) the making of the grant will (A) not result in any decrease in the use of State, local, and other non-Federal funds for services for persons with developmental disabilities and for training of persons to provide such services, which funds would (except for such grant) be made available to the applicant, and (B) be used to supplement and, to the extent practicable, increase the level of such funds; and

"(2) the applicant's program (A) is in compliance with the standards established under subsection (a), or (B) will, not later than three years after the date of approval of the initial application or the date standards are promulgated under subsection (a), whichever is later, comply with such standards.

"(c) The Secretary shall establish such a process for review of applications for grants under section 121 as will ensure that each Federal agency that provides funds for the direct support of the applicant's program reviews the application.

"AUTHORIZATION OF APPROPRIATIONS

"SEC. 123. (a) For the purpose of making grants under section 121, there are authorized to be appropriated $15,000,000 for the fiscal year ending September 30, 1979, $18,000,000 for the fiscal year ending September 30, 1980, and $21,000,000 for the fiscal year ending September 30, 1981.

"(b) Of the sums appropriated under subsection (a), not less than—

"(1) $9,000,000 for the fiscal year ending September 30, 1979,

"(2) $10,000,000 for the fiscal year ending September 30, 1980, and

"(3) $11,000,000 for the fiscal year ending September 30, 1981,

shall be made available for grants under section 121 (a) to qualified applicants which received grants under section 121 (a) during the fiscal year ending September 30, 1978. The remainder of the sums appropriated for such fiscal years shall be made available as the Secretary determines, except that not less than 40 percent of such remainder shall be made available for grants under section 121 (b).".

(b) Section 103 (c) is amended—

(1) by striking out "university-affiliated facility or a satellite center" and inserting in lieu thereof "university affiliated program"; and

(2) by striking out "a project" and inserting in lieu thereof "a program".

(c) Section 112(a) is amended by striking out ", facility,".

AUTHORIZATION AND ALLOTMENTS FOR FACILITY GRANTS

SEC. 10. (a) The text of section 131 is amended to read as follows:

"SEC. 131. For allotments under section 132, there are authorized to be appropriated $60,000,000 for the fiscal year ending September 30, 1979, $75,000,000 for the fiscal year ending September 30, 1980, and $90,000,000 for the fiscal year ending September 30, 1981.".

(b) Section 132(a) is amended—

(1) by striking out subparagraph (B) of paragraph (1) and paragraphs (2), (3), and (4);

(2) by striking out "(A)" in paragraph (1)(A) and by redesignating clauses (i) through (iii) of such paragraph as subparagraphs (A) through (C), respectively; and

(3) by inserting at the end thereof the following new paragraph:

"(2) For any fiscal year, the allotment under paragraph (1)—

"(A) to each of the Virgin Islands, American Samoa, Guam, the Northern Mariana Islands, or the Trust Territory of the Pacific Islands may not be less than $100,000, and

"(B) to any other State may not be less than the greater of $250,000 or the amount of the allotment (determined without regard to subsection (d)) received by the State for the fiscal year ending September 30, 1978.".

(c) Subsections (b) and (c) of section 132 are amended by striking out "134" and inserting in lieu thereof "133" each place it appears.

STATE PLANS FOR PROVISION OF SERVICES AND FACILITIES

SEC. 11. (a) Subsection (b) of section 133 is amended to read as follows:

"(b) In order to be approved by the Secretary under this section, a State plan for the provision of services and

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facilities for persons with developmental disabilities must meet the following requirements:

"Provision for State Planning Council and Administration of Plan

"(1) (A) The plan must provide for the establishment of a State Planning Council, in accordance with section 137, for the assignment to the Council of personnel adequate to enable the Council to carry out its duties under that section, and for the identification of the personnel so assigned.

"(B) The plan must designate the State agency or agencies which shall administer or supervise the administration of the State plan and, if there is more than one such agency, the portion of such plan which each will administer (or the portion the administration of which each will supervise).

"(C) The plan must provide that each State agency designated under subparagraph (B) will make such reports, in such form and containing such information, as the Secretary may from time to time reasonably require, and will keep such records and afford such access thereto as the Secretary finds necessary to verify such reports.

"(D) The plan must provide for such fiscal control and fund accounting procedures as may be necessary to assure the proper disbursement of and accounting for funds paid to the State under this part.

"Description of Objectives and Services

"(2) The plan must—

"(A) set out the specific objectives to be achieved under the plan and a listing of the programs and resources to be used to meet such objectives;

"(B) describe (and provide for the review and revision of the description, not less often than annually) the extent and scope of services being provided, or to be provided, to persons with developmental disabilities under such other State plans for federally assisted State programs as the State has relating to education for the handicapped, vocational rehabilitation, public assistance, medical assistance, social services, maternal and child health, crippled children's services, and comprehensive health and mental health, and under such other plans as the Secretary may specify;

"(C) for each fiscal year, assess and describe the extent and scope of priority services (as defined in section 102(8)(B)) being or to be provided under the plan in the fiscal year; and

"(D) establish a method for the periodic evaluation of the plan's effectiveness in meeting the objectives described in subparagraph (A).

"Use of Funds

"(3) The plan must contain or be supported by assurances satisfactory to the Secretary that—

"(A) the funds paid to the State under section 132 will be used to make a significant contribution toward strengthening services for persons with developmental disabilities in the various political subdivisions of the State;

"(B) part of such funds will be made available by the State to public or nonprofit private entities;

"(C) such funds will be used to supplement and, to the extent practicable, to increase the level of funds that would otherwise be made available for the purposes for which Federal funds are provided and not to supplant such non-Federal funds; and

"(D) there will be reasonable State financial participation in the cost of carrying out the State plan.

"Provision of Priority Services

"(4) (A) The plan must—

"(i) provide for the annual examination of the provision, and the need for the provision in the State of the four different areas of priority services (as defined in section 102(8) (B)); and "(ii) provide for the development, not later than the second year in which funds are provided under the plan after the date of enactment of this paragraph, and the timely review and revision of a comprehensive statewide plan to plan, financially support, coordinate, and otherwise better address, on a statewide and comprehensive basis, unmet needs in the State for the provision of at least one of the areas of priority services, such area or areas to be specified in the plan.

"(B) (i) Except as provided in clause (iii), the plan must provide that not less than $100,000 or 70 per centum of the amount available to the State under section 132, whichever is greater, will be allocated, as provided in clause (ii), to the areas of priority services specified under subparagraph (A) (ii).

"(ii) For any year in which the sums appropriated under section 131 do not exceed—

"(I) $60,000,000, not less than $100,000 or 70 per centum of the amount available to the State under section 132, whichever is greater, must be allocated to no more than two areas of priority services specified under subparagraph (A) (ii), or

"(II) $90,000,000, not less than $100,000 or 70 per centum of the amount available to the State under section 132, whichever is greater, must be allocated to

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no more than three areas of priority services specified under subparagraph (A) (ii).

"(iii) A State plan, in order to comply with clause (i) for a fiscal year, is not required to reduce the amount available to the State under section 132 which is allocated to planning below the amount so allocated in the preceding fiscal year, if substantially the remainder of the amount available to the State, which is allocated for other than administration, is allocated to the areas of priority services specified under subparagraph (A) (ii).

"(D) The plan must provide that special financial and technical assistance shall be given to agencies or entities which are providing or are planning to provide priority services specified under subparagraph (A) (ii) for persons with developmental disabilities who are residents of geographical areas designated as urban or rural poverty areas.

"Standards for Provision of Services and Protection of Rights of Recipients of Services

"(5) (A) The plan must provide that services furnished, and the facilities in which they are furnished, under the plan for persons with developmental disabilities will be in accordance with standards prescribed by the Secretary in regulations.

"(B) The plan must provide that services are provided in an individualized manner consistent with the requirements of section 112 (relating to habilitation plans).

"(C) The plan must contain or be supported by assurances satisfactory to the Secretary that the human rights of all persons with developmental disabilities (especially those persons without familial protection) who are receiving treatment, services, or habilitation under programs assisted under this title will be protected consistent with section 111 (relating to rights of the developmentally disabled).

"Professional Assessment and Evaluation Systems

"(6) The plan must provide for—

"(A) an assessment of the adequacy of the skill level of professionals and paraprofessionals serving persons with developmental disabilities in the state and the adequacy of the State programs and plans supporting training of such professionals and paraprofessionals in maintaining the high quality of services provided to person with developmental disabilities in the state; and

"(B) the planning and implementation of an evaluation system (in accordance with section 110(a)).

"Additional Information and Assurances Required by Secretary

"(7) The plan also must contain such additional information and assurances as the Secretary may find necessary to carry out the provisions and purposes of this part.".

(b) Section 133(d)(2) is amended by striking out "during the fiscal year ending June 30, 1975" and inserting in lieu thereof "during the previous fiscal year".

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STATE PLANNING COUNCILS

SEC. 12. (a) Section 137 (a) is amended—

(1) by inserting "higher education training facilities," after "representatives of the principal State agencies," in the third sentence; and

(2) by amending the fourth sentence to read as follows:

"Of the members of the Council—

"(1) at least one-sixth shall be persons with developmental disabilities or with a milder form of such disability, and

"(2) at least one-sixth shall be immediate relatives or guardians of persons with mentally impairing developmental disabilities,

who are not employees of any State agency or of any other entity which receives funds or provides services under this part.".

(b) Section 137 (b) is amended to read as follows:

"(b) Each State Planning Council shall—

"(1) supervise the development of and approve the State plan required by this part, including the specification of priority service areas under section 132 (b) (4) (A) (ii);

"(2) monitor, review, and evaluate, not less often than annually, the implementation of such State plan;

"(3) to the maximum extent feasible, review and comment on all State plans in the State which relate to programs affecting persons with developmental disabilities;

"(4) promote planning for training of personnel needed to provide services (including advocacy and training in consumer participation) to persons with developmental disabilities; and

"(5) submit to the Secretary, through the Governor, such periodic reports on its activities as the Secretary may reasonably request, and keep such records and afford such access thereto as the Secretary finds necessary to verify such reports.

The State shall provide, to the maximum extent feasible, an opportunity for the State Planning Council to prior review and comment on all its State plans described in paragraph (3).".

(c) Section 137 is amended by striking out subsection (c).

SPECIAL PROJECT GRANTS

SEC. 13. (a) Section 145 is amended—

(1) by inserting "(particularly priority services)" after "otherwise improving services" in subsection (a) (1);

(2) by striking out ", including programs" and all

that follows through the semicolon at the end of paragraph (1) of subsection (a) and inserting in lieu thereof "; and";

(3) by striking out "subsection (d)" in subsections (e) and (f) and inserting in lieu thereof "subsection (e)" each time it appears;

(4) by redesignating subsections (b) through (f) as subsections (c) through (g), respectively; and

(5) by inserting after paragraph (1) of subsection (a) the following (and redesignating paragraphs (2) through (9) of subsection (a) as paragraphs (1) through (8), respectively):

"(2) demonstrations (and research, training, and evaluation in connection therewith) for establishing programs which hold promise of expanding or otherwise improving protection and advocacy services related to the statewide protection and advocacy system (described in section 113).

"(b) Grants provided under subsection (a) shall include grants for—".

(b) Section 145(e), as so redesignated, is amended to read as follows:

"(e) For the purpose of making payments under grants under subsection (a), there are authorized to be appropriated $25,000,000 for the fiscal year ending September 30, 1979,

$28,000,000 for the fiscal year ending September 30, 1980, and $31,000,000 for the fiscal year ending September 30, 1981.".

TECHNICAL AND CONFORMING AMENDMENTS

SEC. 14. (a) Section 112 is amended—

(1) by striking out "after September 30, 1976," in subsection (a);

(2) by striking out "Such" in subsection (b)(3) and inserting in lieu thereof "The"; and

(3) by striking out "an" before "objective criteria" in clause (B) of subsection (b)(3).

(b) Section 134 is amended—

(1) by striking out "CONSTRUCTION," in its heading.

(2) by striking out "(a)" in subsection (a), and

(3) by striking out subsection (b).

(c) Section 135 is amended—

(1) by striking out "CONSTRUCTION," in its heading;

(2) by striking out "(a)" in subsection (a); and

(3) by striking out subsection (b).

EFFECTIVE DATE

SEC. 15. The amendments made by this Act shall apply to payments under title I of the Mental Retardation Facilities and Community Mental Health Centers Construction

Act of 1963 for fiscal years beginning on and after October 1, 1978.

95th CONGRESS
1st Session

H. R. 278

IN THE HOUSE OF REPRESENTATIVES

January 4, 1977

Mr. Conte introduced the following bill; which was referred to the Committee on Interstate and Foreign Commerce

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A BILL

To provide for accelerated research and development in the care and treatment of autistic children, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the "Autistic Children Research Act".

AMENDMENT TO THE PUBLIC HEALTH SERVICE ACT

Sec. 2. Part E of the Public Health Service Act is amended by adding at the end thereof the following:

"RESEARCH PROGRAM ON AUTISM

"Sec. 446. (a) The Director of the National Institute of Child Health and Human Development shall—

"(1) plan and develop a coordinated autism research program encompassing the programs of the National Institutes of Health and related programs of other research institutes, and other Federal and non-Federal programs;

"(2) collect, analyze, and disseminate all data useful in the prevention, diagnosis, and treatment of autism; and

"(3) establish comprehensive, coordinated diagnostic and evaluation procedures that provide for early detection and effective guidance for autistic children.

"(b) There are authorized to be appropriated to carry out the purposes of this section such sums as may be necessary.

"LEARNING AND CARE CENTERS

"SEC. 447. (a) The Secretary may make grants, loans, and loan guarantees to any public or private nonprofit entity operating or proposing to operate a residential or nonresidential center with education programs for autistic children.

"(b) A grant, loan, or loan guarantee under this section may be made only after the Secretary approves a plan submitted by such entity submitted in such form and containing such information as the Secretary may require.

"(c) There are authorized to be appropriated to carry out the provisions of this section $500,000 for fiscal year 1977 and $5,000,000 per annum for fiscal years 1978, 1979, 1980, and 1981.

"(d) For the purposes of this section and section 446 the term 'autistic' means, but is not limited to, those afflicted with infantile autism (Kanner's syndrome), profound aphasia, childhood psychosis, or any other condition characterized by severe deficits in language ability and behavior and by the lack of ability to relate appropriately to others."

95th CONGRESS
1st Session

H. R. 2151

IN THE HOUSE OF REPRESENTATIVES

January 19, 1977

Mr. Roe introduced the following bill; which was referred to the Committee on Interstate and Foreign Commerce

---

A BILL

To provide for accelerated research and development in the care and treatment of autistic children, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the "Autistic Children Research Act".

AMENDMENT TO THE PUBLIC HEALTH SERVICE ACT

Sec. 2. Part E of the Public Health Service Act is amended by adding at the end thereof the following:

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"(2) collect, analyze, and disseminate all data useful in the prevention, diagnosis, and treatment of autism; and

"(3) establish comprehensive, coordinated diagnostic and evaluation procedures that provide for early detection and effective guidance for autistic children.

"(b) There are authorized to be appropriated to carry out the purposes of this section such sums as may be necessary.

"LEARNING AND CARE CENTERS

"SEC. 447. (a) The Secretary may make grants, loans, and loan guarantees to any public or private nonprofit entity operating or proposing to operate a residential or nonresidential center with education programs for autistic children.

"(b) A grant, loan, or loan guarantee under this section may be made only after the Secretary approves a plan submitted by such entity submitted in such form and containing such information as the Secretary may require.

"(c) There are authorized to be appropriated to carry out the provisions of this section $500,000 for fiscal year 1976 and $5,000,000 per annum for fiscal years 1977, 1978, 1979, and 1980.

"(d) For the purposes of this section and section 446 the term 'autistic' means, but is not limited to, those afflicted with infantile autism (Kanner's syndrome), profound aphasia, childhood psychosis, or any other condition characterized by severe deficits in language ability and behavior and by the lack of ability to relate appropriately to others."

95th CONGRESS
1st Session

H. R. 10059

IN THE HOUSE OF REPRESENTATIVES

November 4, 1977

Mr. Roe (for himself, Mrs. Burke of California, Mr. John L. Burton, Mr. Corman, Mr. Downey, Mr. Drinan, Mr. Gilman, Mr. Mazzoli, Mr. Metcalfe, Mr. Moffett, and Mr. Stark) introduced the following bill; which was referred to the Committee on Interstate and Foreign Commerce

---

A BILL

To provide for accelerated research and development in the care and treatment of autistic children, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the "Autistic Children Research Act".

AMENDMENT TO THE PUBLIC HEALTH SERVICE ACT

Sec. 2. Part E of the Public Health Service Act is amended by adding at the end thereof the following:

"RESEARCH PROGRAM ON AUTISM

"Sec. 446. (a) The Director of the National Institute of Child Health and Human Development shall—

"(1) plan and develop a coordinated autism research program encompassing the programs of the National Institutes of Health and related programs of other research institutes, and other Federal and non-Federal programs;

"(2) collect, analyze, and disseminate all data useful in the prevention, diagnosis, and treatment of autism; and

"(3) establish comprehensive, coordinated diagnostic and evaluation procedures that provide for early detection and effective guidance for autistic children.

"(b) There are authorized to be appropriated to carry out the purposes of this section such sums as may be necessary.

"LEARNING AND CARE CENTERS

"SEC. 447. (a) The Secretary may make grants, loans, and loan guarantees to any public or private nonprofit entity operating or proposing to operate a residential or nonresidential center with education programs for autistic children.

"(b) A grant, loan, or loan guarantee under this section may be made only after the Secretary approves a plan submitted by such entity submitted in such form and containing such information as the Secretary may require.

"(c) There are authorized to be appropriated to carry out the provisions of this section $500,000 for fiscal year 1978 and $5,000,000 per annum for fiscal years 1979, 1980, 1981, and 1982.

"(d) For the purposes of this section and section 446 the term 'autistic' means, but is not limited to, those afflicted with infantile autism (Kanner's syndrome), profound aphasia, childhood psychosis, or any other condition characterized by severe deficits in language ability and behavior and by the lack of ability to relate appropriately to others.".

Mr. ROGERS. Our first witnesses are from the Department of Health, Education, and Welfare, Mr. Robert Humphreys, the Commissioner of Rehabilitation Services Administration, Office of Human Development Services, and Mr. Francis Lynch, Director of the Office of Developmental Disabilities. We welcome you gentlemen. Your statements will be made a part of the record in full and you may proceed as you like.

STATEMENT OF ROBERT R. HUMPHREYS, COMMISSIONER, REHABILITATION SERVICES ADMINISTRATION, OFFICE OF HUMAN DEVELOPMENT, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE, ACCOMPANIED BY FRANCIS LYNCH, DIRECTOR, OFFICE OF DEVELOPMENTAL DISABILITIES, OFFICE OF HUMAN DEVELOPMENT

Mr. HUMPHREYS. Thank you, Mr. Chairman and members of the subcommittee.

I am most pleased to appear before you today, for the first time since becoming Commissioner of the Rehabilitation Services Administration, to provide an overview of the programs under the Developmental Disabilities Act, and to present our recommendation that the program be extended for 2 years.

The administration believes that the developmental disabilities program has been successful in helping the States to plan, evaluate, and implement service programs to assist the developmentally disabled to achieve maximum functional skills attainable within the least restrictive environment.

Before I begin my testimony, I wish to reaffirm for the record a few statements I expressed in an interview shortly after I was sworn in as Commissioner on November 7, 1977.

In accepting this assignment, I intend to be an advocate for all disabled populations of our Nation and for programs that are designed to serve them.

All Rehabilitation Services Administration programs, including the recently acquired developmental disabilities program, exist only for the benefit of those who are disabled. I might add they do benefit society as well.

I am a strong believer in consumer participation in the development of policy, planning, and programs.

I am attempting to develop the Rehabilitation Services Administration office as a coordinative and support office which is involved with the total needs of the disabled. It is not surprising that after 6 months of service in this position, I hold these same views today.

The Developmental Disabilities Act enables the Federal Government to assist in providing the coordination of services to a population which has a complexity of service needs and helps to marshall and coordinate resources, both human and financial, so that the most efficient, effective service delivery and program direction may be attained.

This act also has enabled the States to develop a data base for understanding the disabled population's needs, develop new services and model programs, enlist maximum consumer participation and advocacy for the protection of the rights of the disabled.

The present legislation, Public Law 94–103, was passed in October 1975 as the Developmentally Disabled Assistance and Bill of Rights Act and its major provisions are:

It provides support to the States for a wide range of diversified services in terms of lifetime human needs of persons with developmental disabilities.

The basic goal of the act is to provide for a significant improvement in the quality, scope, and extent of services for persons with developmental disabilities by means of:

Comprehensive State planning for the current and future needs of the DD population; coordination and appropriate integrated utilization of existing services and resources for the developmentally disabled at all levels of government and in the private sector; develment and demonstration of new programs designed to fill existing gaps in services and of specialized resources to strengthen and expand present service capabilities.

The target population of Public Law 94–103 consists of children and adults having substantial and continuing handicaps originating during childhood and attributable to mental retardation, cerebral palsy, epilepsy, autism, severe dyslexia, and other conditions found to be closely related or requiring treatment similar to that required for mental retardation.

It is estimated, as the chairman indicated earlier, that there are in excess of 10 million Americans who have developmental disabilities and over 5 million who can be classified as substantially handicapped. The substantially handicapped developmentally disabled population represents almost 2½ percent of the total population of our country.

At this time, as I indicated earlier, the administration is proposing a 2-year extension of the existing Developmental Disabilities Act because we believe that this important program should not be changed before the completion of the studies that were mandated by Congress and are now underway. I will discuss each of these as part of an overview of the administration of the act, as well as your bill, Mr. Chairman, H.R. 11764.

In addition, I might interject, we believe it is essential to limit the expansion of the act at this time because we feel that a number of things are impinging on the devlopment of services and approaches toward meeting the needs of the disabled population, both within HEW and without.

We have had a White House Conference on Handicapped Individuals which made a number of recommendations. Under reorganization within HEW the Rehabilitation Services Administration, I hope, will become a major focus for the disabled within the Federal Government. So, there are a number of things that I think we have to take into account in developing our policy and our planning for this population as well as the total population of disabled citizens.

The present act, Public Law 94–103, is divided into four parts. Each of these parts contains important program elements for individuals with developmental disabilities. I would like to review each of these parts explaining the program progress we have made and share with you the plans for the future.

PART A—GENERAL PROVISIONS

This part of the act provides for two essential State programs for the disabled: A habilitation plan for each individual with developmental disabilities, section 112, and a protection and advocacy program, section 113, administered by each participating State.

Service programs have begun to develop and use individual habilitation plans. Persons with developmental disabilities are benefiting from them. Those are taken from the concept developed under the Rehabilitation Act of 1973, the individually written rehabilitation program which has proved to be so successful in aiding the client.

The Department is in the process of completing instructions to States in the assessment for client growth and development which will aid in the standardization of habilitation plans. This effort will be completed in the next 2 years and made available nationwide.

Each State participating in the program was to have in place a protection and advocacy system by October 1, 1977. The protection and advocacy program is intended to insure that the rights of each disabled individual are protected and that each person receives services when and as they are needed. The protection and advocacy program also protects individuals from getting lost in a complex service system, which involves several public and private service agencies and from inappropriate placement.

We are proud to report that 53 of 54 States and Territories had approved plans for their protection and advocacy system by the required date of October 1, 1977. A variety of aids, such as guidelines and checklists, were provided by the Department, as well as early and continuing training and technical assistance.

The protection and advocacy programs are now in operation and early reports of their activities indicate that they are successful. However, because the protection and advocacy programs have only been in operation since October 1, 1977, just 6 months, we believe it is necessary to allow these programs to mature before measurement of their effectiveness can be realized. We plan to do that this year.

PART B—UNIVERSITY AFFILIATED FACILITIES

The university affiliated facilities program has developed many model programs of services to the developmentally disabled over the years. The university affiliated facilities also play an essential role in providing interdisciplinary training for personnel needed in services for individuals with developmental disabilities. It is important that this program be continued.

The Department is in the process of evaluating the university affiliated facilities program, more clearly defining its relationship to and coordinating with similar maternal and child health programs, and will develop performance standards for this activity.

As you know, UAFs are supported both through the developmental disabilities program and maternal and child health programs. We will help to develop program performance standards for this activity.

Upon completion of the evaluation and coordination studies, the Department will recommend changes to help improve training programs.

With the introduction of the Developmental Disabilities Office to the Rehabilitation Services Administration, we are beginning to examine the interrelationships that might be established between the UAFs and the research and training centers under that Rehabilitation Act.

PART C—GRANTS FOR PLANNING, PROVISION OF SERVICES AND CONSTRUCTION

The major purpose of the DD act is to provide coordinated services by the States for individuals with developmental disabilities. This coordination, in part, is accomplished through the development of a comprehensive State plan. The comprehensive State plan contains five important areas of information concerning the target population and available services, including: A description of the State DD population; an identification of the service needs by age group; a description of the existing service network including quantity of participants and quality of service; a description of identified gaps in services; and a comprehensive plan containing goals and objectives for filling identified gaps utilizing existing resources within the State.

During the past 2 years, the Department has administered a program to help States develop guidelines for the implementation of the State Plans throughout the Nation. We are pleased to say that every State has responded this year by following the guidelines format.

As a result, the States are learning more about the developmental disabilities population, service network and the service agency objectives than ever before. An analysis and additional experience in this comprehensive planning effort will permit the identification of legislative recommendations in the next few years.

One of the important program components of the Developmental Disabilities Act is the mandated State Planning Council. This council is one of the few examples where consumers have actual input into program and policy decisions. The consumer activity in program planning is of considerable interest to me and basic to the developmental disabilities program.

The State Planning Council supervises the development of the State plan. The act, section 137, requires that one-tihrd of the council be composed of consumers. Also, the act requires State agency directors to be members of the council.

In this way, both the receivers of services and providers of services are involved in the creation of the comprehensive State plan, its implementation and the evaluation of the service system. As I have stated, I believe consumers should have input into programs which affect their lives. The State DD planning council, because of its required inclusion of consumers, is a vital part of the developmental disabilities program.

Let me interject again to indicate that new organization of RSA includes an Office of Advocacy and Coordination, which will adopt for the first time within our agency a major focus where disabled individuals and groups and organizations of individuals can come to have definite input and effect on the entire program of the Federal Government with respect to the programs that affect them.

We are aware that H.R. 11764 presents priorities to which the developmental disabilities community should focus its attention. We would like to have additional time to investigate the basis for these suggested priorities, validate them, and determine the impact that they would have on the target population. The uniqueness of each State and its delivery of services will require careful analysis if specific priorities are to be mandated by law.

We must assure ourselves that these priorities do not duplicate services provided under other Federal or State programs serving the disabled such as maternal and child health. Therefore, more time is required to study these priorities and their impact in relation to the needs of our population.

I might say in reviewing those priorities, at first review, they looked most meaningful and important and reflect in a smaller way my directions for the entire program for the disabled.

PART D—SPECIAL PROJECT GRANTS

The Department has been active in increasing technical knowledge, assisting State councils and service agencies and exporting model programs for general utilization through the use of special project grants. Because of their significance, I want to cite the following examples of the development of our technical knowledge:

Identification of characteristics of the residents and those individuals released by long-term care facilities for the mentally retarded and their adjustment to the community setting.

Development of model diagnostic and training techniques for hearing impaired developmentally disabled persons.

Identification and evaluation of the quantity and quality of minority participation in the development disabilities movement.

Development of expertise and knowledge concerning the problems of aging and the aged developmentally disabled.

Development of community based agency capable of furnishing an array of residential and other service/alternatives.

These research efforts have provided the Department with knowledge and service models that aid the developmentally disabled. We are particularly interested in getting these newly created models to service agencies in an orderly and timely fashion.

The Department has also been diligent in providing information and assistance to significant groups involved with the developmentally disabled. We have developed technical assistance programs to:

Assist Federal agencies which have the potential for expanding or improving their services to the developmentally disabled.

Train the State DD councils or subsets or units of the councils; State DD council planners and other council staff.

State planning councils and voluntary agencies on the utilization of other Federal programs.

Design and implement a national/regional strategy for training and technical assistance in comprehensive planning and evaluation.

It is important that the special projects extend our knowledge concerning our population and also develop assistance for the groups involved with the population. We have accomplished both of these tasks through the special projects grants.

Studies and recommendations: I am happy to report to the Congress that the Department has compiled with the DD Act's requirements that certain studies be conducted. We have completed a review and evaluation of the standards and quality assurance mechanisms applicable to individuals with developmental disabilities and developed model standards for programs for persons with developmental disabilities.

Also, there is a quality assurance mechanism for implementing the standards. At present, we are studying the feasibility and implementation strategy for the model standards. This effort will be concluded by the end of fiscal year 1980.

Also, the Department has completed the study of the definition of developmental disabilities which was authorized by Congress in Public Law 94–103. Congress authorized a national task force on the definition of developmental disabilities. The majority of the task force recommended a relatively significant expansion of the definition, while a sizable minority recommended a definition closer to that of the current law.

We believe that for the time being, the existing definition should be retained until we have had an opportunity to analyze the impact which the majority opinion would have on our population. We have initiated a study to determine the impact of such a significant change, and the report should be available to Congress within the next 2 years.

I might add that the Department as a whole has under consideration, and it has had for some time now, the possibility of establishing a uniform definition throughout the Department for programs on disability. The same issue is under consideration with respect to the Rehabilitation Act. It is a very complex kind of problem and I think that in that context, the definition of the developmentally disabled should also await our study of that area.

Finally, we have concluded the evaluation of the social and legal issues of the confidentiality of records for our clients and as assessment instruction for client growth and development. We are in the process of developing an overall design and specifications for an evaluation system.

The Department has available summary results of the comprehensive State plans for fiscal year 1978 as compiled from the DDEIS format. Also, we have available the detailed reports from the special studies which were mandated in the act. We have made some presentations to your staff and would be pleased to be available for any additional meetings in the future. We believe that we have made significant progress in the last 3 years in providing services for individuals with developmental disabilities.

In addition to a 2-year extension, the administration is requesting through the budget process $61.9 million for fiscal year 1979 and in the authorization such sums as are necessary for fiscal year 1980.

Specifically, we are requesting the following amount for each of the program components:

Section 113(b)(2)—protection and advocacy program, $3 million; section 123(a)—university affiliated programs, $6.5 million; section 131—basic State grants, $46.9 million—this is an increase of $16.8

million over the appropriated amount in fiscal year 1978; section 145—special project grants, $5.5 million.

We intend to work closely with the subcommittee to improve State services and the service delivery system for the benefit of individuals with developmental disabilities. I appreciate this opportunity to testify and look forward to assisting you in the future.

I shall be happy to answer any questions.

Mr. **Rogers.** Thank you very much. That is a helpful statement.

I might say it would be helpful to the committee if you could state a specific figure for 1980 and 1981. I realize you recommend such sums but this committee will write in specific amounts.

Mr. **Humphreys.** As I indicated, Mr. Chairman, we are proposing a 2-year extension for 1979 and 1980 and presumably the level for 1980 would reflect the budget request and we would anticipate a level funding for that purpose of $61.9 million.

Mr. **Rogers.** For 1980?

Mr. **Humphreys.** Yes.

Mr. **Rogers.** And for 1981?

Mr. **Humphreys.** For 1981 we are not recommending any level because we are only asking for a 2-year extension.

Mr. **Rogers.** What I am saying is that it would be helpful to us to have a figure for that.

Mr. **Humphreys.** We can provide that for the record.

Mr. **Rogers.** Thank you.

[The following information was received for the record:]

Because of our expectation that the nature of the act would be modified substantially as a result of our review over the next 2 years, and assuming that the committee will agree to a simple 2-year extension, we are not in a position to recommend a funding level for fiscal year 1981.

Mr. **Rogers.** Dr. Carter.

Mr. **Carter.** Thank you, Mr. Chairman.

I want to compliment the gentleman on his excellent presentation. I am particularly impressed by the fact that you mentioned dyslexia, which is something on which I want to focus a little bit more. What is your estimate of how many persons would be added to the "DD" program coverage if the task force's recommended definition were to be adopted?

Mr. **Humphreys.** You are speaking of the majority report?

Mr. **Carter.** Yes. Of course, that is the recommendation. But I got the impression that you did not want to follow either the majority or the minority report according to what you said.

Mr. **Humphreys.** At the moment, no.

Mr. **Carter.** If you adopted the majority position, which I think would be the logical thing to do, how many more people would be included in the developmental disabilities program?

Mr. **Humphreys.** It is really quite difficult to know that. Right now there are varying and different interpretations of who are included in the DD population. The study was an attempt to really narrow the focus and at the same time expand it. The narrowing would be in focusing on those in the DD population who are more substantially disabled. The expansion then, of course, would relate to disabilities other than mental retardation, cerebral palsy, autism, dyslexia and epilepsy, which are developmental in nature and occur prior to the age of the majority.

Mr. CARTER. They are part of the law at the present time.

Mr. HUMPHREYS. Yes; they are.

Mr. CARTER. How successful have the State DD programs been in generating new sources of support for persons with developmental disabilities as compared with efforts to increase access to existing services through better coordination at the State level? Have you been able to generate new sources of support at the State level?

Mr. HUMPHREYS. There have been successes in that area, certainly. As the respect at the State level for the Developmental Disabilities Council increases and as their effectiveness increases, their capacity also increases to have an impact on other State programs.

Mr. CARTER. You have noticed then increases in appropriations by the States for these developmental disabilities programs?

Mr. HUMPHREYS. If I may, Dr. Carter, ask Mr. Lynch to respond to the specifics.

Mr. LYNCH. Yes; in both instances in terms of increases in State general revenue dollars and access from other Federal-State programs we have noted an increase. We can provide you with an analysis based on our recent work done with the fiscal year 1978 State plans in that area.

Of more significance in terms of the ability to access funds the protection and advocacy program, for example, has in a very short period of time gathered other resources in terms of State general revenue sharing and other public and private sources. In Illinois, as an example, the protection and advocacy program got $1 million from general revenue to conduct a protection and advocacy program in excess of the base amount available in that State to finance that program.

Mr. CARTER. Do you follow these programs down to the State level to see how they work?

Mr. LYNCH. Yes.

Mr. CARTER. How well are the States complying with the law? Are they enacting good programs to aid the developmentally disabled?

Mr. HUMPHREYS. Many are doing so. Some, of course, are not. There is really no uniformity.

Mr. CARTER. Are those which are not conducting good programs still receiving funding from the Federal Government?

Mr. HUMPHREYS. The funding that they receive through this program is, of course, in the nature of coordinating dollars. It is not really service delivery dollars. The expectation is that the DD money will aid the States in developing a recognition and a sensitivity to the needs of this population and will, as a result of that, increase their resources directed to the developmentally disabled. Some are more receptive than others, quite simply.

Mr. CARTER. There are some service dollars in there.

Mr. HUMPHREYS. Yes; but its primary purpose is to serve as a catalyst for bringing together the resources of a number of programs, at least nine, under the law.

Mr. CARTER. We have many schools for the mentally retarded. Do service funds go to them or not?

Mr. HUMPHREYS. There are funds, of course, provided under a number of different acts. I do not believe that the service dollars under the DD program go specifically for schools for the mentally retarded. Mr. Lynch can answer that more specifically, I think.

Mr. **Lynch.** No; not directly in terms of service. But in terms of developing the institutionalization plan for the State, for the State public institutions for the mentally retarded, there are DD dollars invested in terms of planning and in terms of the identification of that State plan.

Mr. **Carter.** But not many service dollars? Most of it is at the planning and coordinating levels. Now, I would like to ask you how much money you are spending on osteogenetic dysplasia.

Mr. **Humphreys.** I think probably none, unless it is associated with another disability covered under the act which results in multiple handicaps.

Mr. **Carter.** We have people with osteogenetic dysplasia who have multiple handicaps. It implies multiple handicaps. It is very difficult for them to move around. Are we doing anything for them?

Mr. **Humphreys.** Yes; indeed, but not enough for any disability. In the area of rehabilitation, departing somewhat from the purpose of the current testimony, I cannot give you numbers. But each disabled individual who has a reasonable expectation of employment capacity may be determined eligible by a State Vocational Rehabilitation agency for services. There are, of course, dollars available under title XX.

Mr. **Carter.** Not from this?

Mr. **Humphreys.** That is correct. Unless there is a relationship to the primary disorder, a developmental disorder.

Mr. **Carter.** Of course there is a relationship to it. These are developmental disorders. People are born with them.

Mr. **Humphreys.** Yes; but under the law the only ones that are susceptible of being provided those services and that coordination are those four major categories.

Mr. **Carter.** That is right. Under this legislation it does not go very far or do very much.

Mr. **Humphreys.** I could not agree with you more that we need to do a great deal more for all our disabled population whether through this act or another.

Mr. **Carter.** Thank you.

Mr. **Rogers.** Mr. Ottinger.

Mr. **Ottinger.** Thank you, Mr. Chairman.

I wonder if you can give us figures on what the impact would be of eliminating the age 22 limitation which presently exists and which is recommended to be continued by both the majority and minority task force reports, what the impact would be if we specifically were to include multiple sclerosis, and give us some idea of what programs are available presently for multiple sclerosis victims?

I have the impression that these people are particularly underserved and have frequently been underserved.

Third, if you would comment on S. 2600, the amount provided under that legislation and whether you think the amounts there authorized are adequate to take care of the expanded scope of the program that is contemplated.

Mr. **Humphreys.** Thank you, Mr. Ottinger. I will certainly respond to each of those.

First, I think I need to know with somewhat more specificity what you mean by removing the age lmit. Do you mean that in the context of the population that is included within the current definition or the proposed definition?

Mr. OTTINGER. That is right. If we were to broaden the definition so that the specific diseases covered mental retardation—maybe that is not properly defined as a disease, but a disability—mental retardation, autistic behavior, cerebral palsy, dyslexia, if we broaden that so that they would not have to be as ascertained before the age 22 but were covered at whatever age the person was inflicted with that disability, what the impact would be, how much more money would be needed to enable you to provide meaningful programs that are directed at these problems for people who are afflicted with these particular diseases as adults.

Mr. HUMPHREYS. Let me suggest that inasmuch as these categories of disabilities are for the most part by their nature developmental, the effect of removing that age limit per se would probably have very little effect. I could perhaps get a more specific answer to that from Mr. Lynch.

Mr. LYNCH. Yes; the question of the cutoff at 22 or 18 was addressed in our definition study. It came through in S. 2600. We would have to make an assessment of what the numbers would be by increasing the age of one's disability.

Mr. OTTINGER. Can you do that for us in a fairly short time frame so that we could make that consideration knowledgeably?

Mr. HUMPHREYS. We will attempt to do that quickly for the record, Mr. Ottinger.

[The following information was received for the record:]

It does not appear that the number of individuals defined as developmentally disabled would increase substantially. (+5 percent)

Mr. OTTINGER. What about adding multiple sclerosis, which I understand is a disease which is generally not apparent until an older age?

Mr. HUMPHREYS. I do not think the genesis of multiple sclerosis is generally known or when its onset begins. Certainly, I agree with you that multiple sclerosis, along with other specific disabilities, have been underserved by our programs in the past.

Quite recently, I concluded with the National Multiple Sclerosis Society an agreement to provide greater emphasis on joint efforts toward services for the population who have multiple sclerosis. I can provide a copy of that memorandum of agreement for the record if you wish.

Mr. OTTINGER. What kind of impact would it have and what additional resources would you need if we were to add multiple sclerosis specifically to this legislation?

Mr. HUMPHREYS. The total "MS" population, as I recall, is something around 500,000. If we were to mandate services coordination for that population, my assumption would be then that that would increase the total population covered under the existing definition by roughly 5 percent.

Therefore, the additional population would not be that great.

[Testimony resumes on p. 71.]

[Questions from Congressman Ottinger and Mr. Humphreys' responses follow:]

Questions From Congressman Ottinger and Mr. Humphrey's Responses

Q: What would be the impact, in terms of the number of individuals included, of increasing the age of onset of a disability?

A: The National Task Force on the Definition of Developmental Disabilities addressed this issue at the second and third of its meetings and requested that a staff paper be prepared on the issue. Attached is a copy of the issue paper. Summarized below are some of the major points from the paper and the Task Force Final Report:

- The Task Force examined the issues of origination (point at which the condition began or was caused) and manifestation (point at which the condition became evident or was detected) and decided to focus the age of onset on manifestation since it is manifestation which actually affects the development of an individual. This is a change from the current definition which specifies origination.

- The age of onset for most of the disorders identified in the Mott-McDonald study is either before age 20 or after age 30 (p.11). It does not appear that the number of individuals defined as developmentally disabled would increase substantially (+5%) with the change from age 18 to age 22. The Task Force recommended the change to age 22 for the following reasons:

  1. it represents a generally accepted end point of a primary maturational period.

2. it is consistent with a variety of programs (tax, Social Security, welfare, education, etc.) which use this age as a critical point.

Q: What would be the impact on the developmental disabilities program if multiple sclerosis were included as a developmental disability?

A: When national associations were contacted by the National Task Force on the Definition of Developmental Disabilities to request their input into the study, the Multiple Sclerosis Society responded that they felt that multiple sclerosis was not a developmental disability. The manifestation of multiple sclerosis, usually in early adulthood, generally eliminated it from the consideration of the Task Force since there was general agreement that the definition should focus on the developmental period, the crucial maturational period. When multiple sclerosis was diagnosed in the under age 22 population, the Task Force definition would include those individuals within the developmentally disabled population.

The Task Force report specifically mentions multiple sclerosis as a condition which originates early in life but which does not generally manifest itself until adulthood. To quote from the report," Persons with such conditions were considered to be significantly different in terms of their developmental experiences and service needs from those intended to served by the Developmental Disabilities Program" (p. 13, Final Report).

Definition of
Developmental
Disabilities

National Task Force
On the Definition of
Developmental Disabilities
Chairperson:
Norman V. Lourie

AGE OF ONSET: SOME ISSUES

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1.0 INTRODUCTION

During the meetings of the National Task Force on the Definition of Developmental Disabilities, there has been much discussion on the issue of age on onset of developmental disabilities. Some Task Force members prefer the concept of the disability originating between 0-18 years (as in the current definition) while others feel that the cutoff point should be extended to 21 years in order to make the definition more consistent with other federal programs' definitions. Still others felt that since the term developmental includes all stages of life no cutoff should be used.

Related to this question of cutoff points is origination of and manifestation of disability. By origination, we mean the point at which the specific condition actually began or was caused. Manifestation refers to the point at which this condition became evident or was detected. In many cases, a condition originates at birth but is not manifest until later in childhood or even in adulthood. Often, a condition may only be manifest when it has resulted in a limitation in functioning or in a disability--that is, an inability or limitation in performing social roles and activities in relation to work, school, family, or independent living. Some Task Force members feel that the definition should include only those persons with disabilities having their origination and manifestation before the particular cutoff point (18/21/or whatever); others feel that persons with disabilities originating before the cutoff point but not manifesting themselves until later in life should also be included. For example, certain types of epilepsy may originate before age 18, but seizures are not evident until later in life; or in the case of diabetes the condition may occur early in life; but disabilities resulting from it, such as blindness, may not occur until adulthood.

In short, two questions related to this issue need to be resolved by Task Force members at the September meeting:

(1) What age cutoff point, if any, should be used in the definition of developmental disabilities?

(2) If an age cutoff is used should it refer to origination or to manifestation?

The Task Force is faced with five major options regarding these issues.* The definition can include persons with disabilities having:

(1) origination and manifestation before age 18
rationale: in order to maintain focus and intent of original legislation;

(2) origination and manifestation before age 21
rationale: to maintain the childhood disabilities focus yet make the age limit more compatible with other federal and state legislation age limits

(3) origination before age 18, but manifestation after that age
rationale: to include all persons whose disabilities originated before 18, whether or not they were manifested before that point;

(4) origination before age 21, but manifestation after that age
rationale: to include all persons whose disabilities originate before 21, whether or not they were manifested before that point;

(5) origination and manifestation at any point in life
rationale: to include developmental disabilities originating or manifest at any point in life in order to be consistent with the term "developmental" which implies a lifelong process.

This paper addresses these options by examining some of the underlying policy, program and political issues and by presenting, where possible, existing data on technical issues such as the incidence of disabilities by age and the prevalence of disabilities originating during childhood but not manifested until adulthood. This paper is not intended to serve as an exhaustive review of the literature, but rather, as a resource to Task Force members in making their decisions.

The Task Force is faced with two related decisions which are displayed in the following table:

	prior to specific age	at any point in life
originates		
manifests		

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*These particular options are presented because they represent the various approaches which emerged during discussions at the first and second meetings of the Task Force.

Given these decisions there are three main possibilities:

1. Only disabilities both originating and manifesting prior to a specified age will be included.
2. Disabilities originating prior to a specified age but manifesting at any time during a person's life will be included.
3. Disabilities originating and manifesting at any time during a person's life will be included.

This criterion (age on "onset") is one of the descriptors to beused in the definition. Therefore, the Task Force does not necessarily have to include all disabilities which fall into one of the above categories. First, we have attempted to collect data on what the size of the developmentally disabled population would be if different age cutoff points were used. This information will indicate whether the size of the total DD population could change substantially if different age cutoff points were used.

Please note that after each of the subheadings which follow, reference is made to the options (discussed in 1.0) to which the research is most relevent.

2.0 INCIDENCE OF CHILDHOOD DISABILITIES (Option 1)

Information on the incidence of various disabilities by age is difficult, if not impossible, to obtain. There have been some studies of birth defects, but after birth there are few studies conducted to provide an estimate of the occurrence of new cases of impairments. Dempsey explains that "such studies are of next to prohibitive cost and the feasibility of maintaining a highly mobile American population under surveillance for two decades is highly questionable (Dempsey, 1976)".

Experts in the field believe that the origination of virtually all childhood impairments is at birth. Hatfield (1973) found in his study of blind children that over 80 percent were blind from birth. In Dempsey's studies of cerebral palsy (1974), it was found that the base majority of cases suffered brain damage no later than at the time surrounding birth. The Kavai study, in which 1,311 pregnancies were followed until the children were 10 years old, found the majority of the cases of handicapping conditions occurred at birth or during infancy (Bierman *et al*, 1965). Similarly, Wulf *et al*. (1966), in their study of congenital defects in a small, defined Vermont population over a twelve-year period beginning with birth found that 38 of the 56 cases of congenital defects requiring long-term care were diagnosed in the first two years of life. Hakosalo (1973) followed a birth cohort for 10 years; the cumulative incidence frequencies showed a high detection rate of defects in the first year of life, a considerable detection rate of defects until about age 8, and a low detection rate of defects thereafter.

What are the implications of these findings for this study? Since it is generally held that the origination of all childhood impairments is birth or infancy, we can assume that a change in cutoff point from 0-18 to 0-21, or to under 18, would have little effect on the size of the total population included in the definition. A change in cutoff point from 18 years would only be appropriate for reasons unrelated to size of the population. For example, some Task Force members favored a cutoff point of 21 years so that the definition would be compatible with age limits in other legislation. However, an examination of other federal legislation (See "Analysis of Federal Laws" in Background Materials) shows that there is no single age limit applied across the various programs. For example, the Childhood Disability Benefits Program under the Social Security Act, uses the cutoff point of 18; the Early and Periodic Screening, Diagnosis and Treatment Act includes children up to age 21; the Education for All Handicapped Individuals covers children 3-18 years old. Task Force members would need to identify the specific pieces of legislation with which it wishes the definition of developmental disabilities to be compatible before a change in age limit could be formulated.

2.1 Incidence of Disabilities in Adulthood

To examine the implications of eliminating the age cutoff and including specific disabilities originating at any point in life, information on the incidence of these disabilities in adulthood would be useful. These figures would help determine the size of the newly defined developmentally disabled population. However, data on the incidence of disabilities in adulthood are even more scarce than incidence studies of childhood disabilities because of the logistical and financial problems in studying a cohort throughout life. To our knowledge, no study has followed a sample of persons throughout life to determine the incidence of disabilities at each age.

Conceptually, we can discuss two overall types of disabilities of adulthood:

1. conditions which originated in childhood, but are not manifested until adulthood--e.g., Huntington's chorea, certain forms of epilepsy, other hereditary conditions, childhood diabetes, etc.
2. conditions originating and manifesting in adulthood--e.g., accidents, traumatic injury, senility, etc.

The latter disability group occurs more frequently than those in the first group. Because the nature of these groups is so different, they shall be discussed separately.

2.1.1 Disabilities Originating in Childhood/Manifesting in Adulthood (Option 2)

Experts agree that a variety of conditions originate prenatally or at the time of birth but are not manifested until later in life. In Apgar's study (1968) of birth defects, she identified many conditions with delayed manifestation, including some which are not manifested until adulthood. As seen in Table 1, some of the birth defects manifesting at 20 years or later include Huntington's chorea, Alzheimer's presenile psychosis, and diabetes mellectus (late type).

In a draft "Review of the Commonalities and Differences of Various Neurological Disorders" (1977) presented by Mott-McDonald Associates to the Epilepsy and Huntington's Disease Commissions, the age of onset of various neurological disorders was examined. Table 2 lists disorders with age of onset in childhood and in adulthood. The disorders with onset in adulthood included multiple sclerosis, paraplegia, Huntington's disease, Parkinsonism, amyotrophic lateral scherosis, stroke, and alzheimers dimentias.

Flynt (1973) identified the following birth defects which do not generally occur until later in life: hypertension, diabetes, arteriosclerosis, schizophrenia, and gout. Another condition in which manifestation is often delayed is epilepsy. Lenox (1960) (cited in Basic Statistics of the Epilepsies) estimates that only slightly more than three-fourths of people with epilepsy have their first seizure before the age of 20.

We know that a number of conditions exist which originate at birth but are not manifested until adulthood. No study, however, has attempted to estimate the actual incidence or prevalence of these delayed-manifestation conditions. The size of this group of disabilities is unknown but is generally not considered large.

2.1.2 Disabilities Originating and Manifesting in Adulthood (Option 3)

In a report based on data from the Social Security Survey of the Disabled, 1966, the age of onset of various conditions was examined. In this study, the term "onset" referred to the point when the condition was first noticed--that is, the term is synonomous with the term "manifestation" as used in this paper. In Table 3, the age of manifestation of various disabilities is presented by diagnostic condition and functional limitation. From this table, we can examine which types of disabilities most frequently have onsets in adulthood; they are broken down into the following ranges: 18-34, 35-54, 55-64. Treitel summarizes the types of disabilities most common for each of these age range categories:

> A larger proportion of those with onset of disability between age 18 and 34 have musculoskeletal disorders than those with onset of disability at other stages in the life-cycle. Many of these disorders may be due to injuries in accidents and less to diseases which are more prevalent at early and later ages. This group also had a greater proportion with mental illness or nervous trouble than those disabled at other ages. Among the severely disabled, about three times as many persons disabled in early adulthood had a mental illness or nervous condition than those disabled at other ages. However, the greater proportions shown for young disabled adults of both musculoskeletal disorder and mental illness may largely be attributable to the lower risk to these young adults of degenerative diseases associated with aging. The prevalence of these diagnostic categories is not greater for young adults than older persons when the entire civilian population at risk is considered including the nondisabled.
>
> Disorders among persons age 35-54 appear to reflect a growing proportion of degenerative disorders related to aging. There is an increased proportion with cardiovascular conditions. Nearly half who have musculoskeletal disorders have arthritis or rheumatism compared to less than a third of those disabled before age 35.
>
> This trend is increased among those disabled at ages 55-64, with about 40 percent with disorders due to a cardiovascular condition. Among the older disabled, those with onset of

> disability before age 55 had a smaller proportion of heart trouble and high blood pressure as their primary impairment than did persons of the same age with later onset of disability (Treitel, p. 6).

What are the implications of the Treitel report for the Task Force's deliberations on the age of origination? The data show that the types of disabilities with origination and manifestation in adulthood are often quite different from those originating in childhood. If the Task Force decides that the definition should include disabilities occurring in adulthood as well as childhood, the DD program will be dealing with new types of disabled persons--many who became disabled due to injuries in accidents and to degenerative disorders related to aging. The service needs of these groups might be quite different from those traditionally focused on by the DD Program. A comparison of service needs follows in the next section.

3.0 COMPARISON OF SERVICE NEEDS OF VARIOUS GROUPS OF DISABLED PERSONS

Thus far, we have discussed three groups of disabled persons:

(1) children with disabilities originating and manifesting prior to a specified age (generally 18 or 21)

(2) adults with disabilities originating before a specified age (age 18 or 21) but manifesting after that time

(3) adults with disabilities originating and manifesting at any point during life

The main emphasis of the DD Program has been on persons in this first category. In some cases, persons in this second group have been included. Persons in the third group traditionally have been excluded from DD Programs. How different are the needs of the latter two groups? Would the DD Program be able to plan and advocate for their needs as well as those it has traditionally served?

Many people argue that the service needs of these groups are very different, particularly the needs of the first group as contrasted with the latter two groups. As Dempsey (1976) summarizes, "...for the adult population the principal precipitation of disability is seen as the loss of ability to continue to meet long standing demands for the environment...(this is in contrast to) developmentally disabled children who never had certain abilities or who lost abilities early in the developmental years before entering the traditional performance demanding environment of childhood, such as school. For these children there is no loss of abilities which had been used to meet environmental performance demands." Persons who become disabled in adulthood need rehabilitation services. Persons disabled at birth or in childhood need habilitation services--they never had the skills or abilities to which they could then be rehabilitated.

Treitel confirms these findings in his report, claiming that the nature and consequences of disabilities are quite different for children, working-age adults, and older persons. According to the SSA data, 1966, persons disabled in childhood had the following characteristics (pp. 5-6):

> In terms of functional limitations, a greater proportion of the childhood disabled were so functionally limited as to be more physically dependent (23 percent) than those disabled when adults (about 16 percent). Among the severely disabled about half of the childhood disabled were dependent compared to about 30 percent of those disabled later in life.
>
> A smaller proportion of the childhood disabled had minor and moderate degrees of functional limitation but a greater proportion of the childhood disabled were functionally dependent or had no loss. Thus, those disabled in childhood were reported to have more extreme ranges of functional loss than persons who became disabled when adults.

In terms of service needs, Treitel hypothesizes that disabilities occurring in early childhood may lead persons to greater dependency than those persons with disabilities occurring at a later age if they seriously interfere with the individual's education, entry into employment, and social relations. He states:

> From a developmental perspective, people may be seen as passing through a series of social and economic stages in terms of their age: from training for self-maintenance and family life in childhood, to employment and child-raising in adulthood, to retirement at an older age. Impairments may interfere with these progressions and lead to alternative personal and social arrangements. A person disabled in childhood may continue to be dependent on his family when adult; a worker who suffers an injury which prevents employment for an extended period of time may need to establish disability or welfare status in an income maintenance program; an older worker with an impairment may decide on early retirement. (Treitel, 1972, pp. 1-2)

While some persons maintain that the service needs of these groups are inherently different, others argue that their needs are functionally similar. If an adult needs advocacy services or job training or personal care, it doesn't matter if s/he needs it because s/he was disabled at birth, in adolescence, or in adulthood. The important fact remains that certain needs exist for which services must be planned and provided. According to this theory, the commonality of the needs of persons is more important than the origin and manifestation of those needs.

SUMMARY

Based on the data of the various studies described in this report, the following concluding statements can be made:

- It is generally held that the age of origination of all childhood impairments is birth or infancy. Therefore a change in cutoff from 18 to 21 or to below 18 would have little effect on the total size of the population included in the definition.

- It is unclear whether a change from a cutoff point from 18 to 21 would make the definition more "compatible" with other legislation since the cutoff points used in other legislation very considerably.

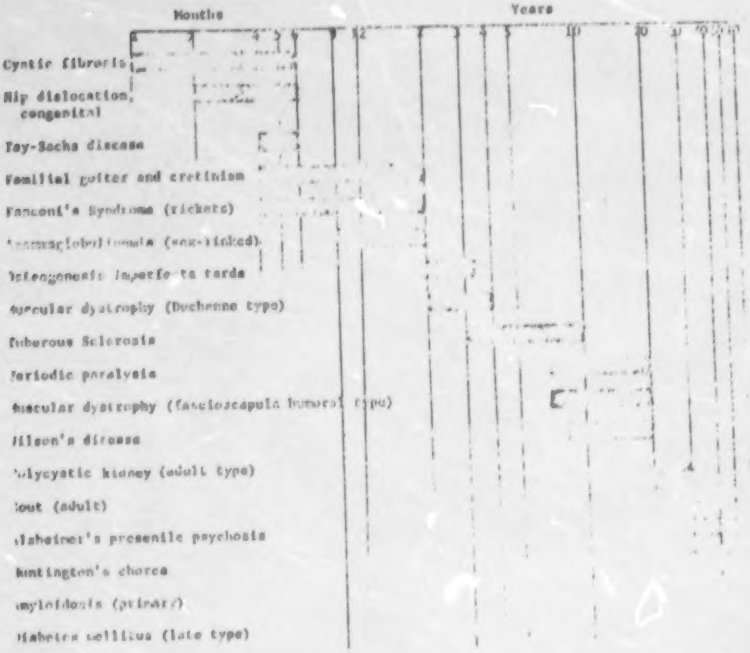
- There are a variety of conditions which originate prenatally or at birth but are not manifested until later in life. No study, however, has attempted to estimate the size of this population. If this group is included in the DD definition, it will be difficult to estimate its impact on the size of the DD populations.

- There is a large variety of disabilities with origination and manifestation after age 18. These types of disabilities in adulthood are quite different than those originating in childhood--particularly with respect to adults becoming disabled due to injuries in accidents and to degenerative disorders related to aging.

- Most experts maintain that the service needs of persons disabled in childhood are frequently quite different than those of persons disabled in adulthood. Disabilities occurring in early childhood tend to interfere more with the individual's opportunities for education, employment, and social relations than disabilities occurring later in life. Habilitation is the primary emphasis of services for persons disabled in childhood; rehabilitation is the focus of services for persons disabled later in life.

TABLE 1

Age Range of Victims at Onset of Late-Appearing Birth Defects



*Appears in Apgar, 1968.

TABLE 2: AGE OF ONSET AND LIFE EXPECTANCY BY DISORDER

Child	Approximate Age of Onset	Average Life After Onset*
Spina Bifida	Birth	Near Normal
Tay Sachs	1st. year	3
Tuberous Sclerosis	1st. year	20
Cerebral Palsy	0-2	Near Normal
Autism	1-3	Near Normal
Mental Retardation	Child	Near Normal
Muscular Dystrophy	3-15	20
Gilles De La Torrette's	2-15	15
Dystonia	5-16	7
Myasthenia Gravis	5-20	Near Normal
Ataxias	8-15	15
Narcolepsy	12-16	Near Normal
Epilepsy	Mostly Children	Near Normal
Schizophrenia	Early Adult	Near Normal
Adult		
Multiple Sclerosis	30	35
Paraplegia	Mostly Adult	Near Normal
Huntington's Disease	35	12
Parkinsonism	Mid 40's	15
Amyotrophic Lateral Sclerosis	50	3
Stroke	60 Ave.	½ Normal (6 yr)
Alzheimers Dementias	Bimodal 45, 75	10

* Assuming receipt of proper services

(Mott-McDonald Associates, June 1977)

TABLE 3

Age at onset of disability by diagnostic condition and functional limitation: ntage distribution of disabled and severely disabled noninstitutionalized adults 18-64, spring 1966

agnostic condition and functional itation by severity of disability	Total	Age at onset of disability			
		Under 18	18-34	35-54	55-64
DISABLED					
Number (in thousands)	17,753	2,718	4,955	7,552	2,030
Diagnostic group and conditions					
Total percent	100.0	100.0	100.0	100.0	100.0
sculoskeletal disorders	30.9	22.0	37.4	32.0	25.9
Arthritis or rheumatism	12.4	2.4	12.0	15.3	16.2
Back or spine	11.0	7.6	15.8	11.3	6.4
Impairment of limbs	4.9	9.1	6.5	3.3	2.6
rdiovascular disorders	24.8	11.8	16.7	30.4	40.1
Heart trouble	11.4	4.3	5.1	15.9	20.3
High blood pressure	5.4	1.3	2.3	7.1	10.2
espiratory and related disorders	[illegible]	20.3	12.3	8.1	6.4
Asthma	3.8	9.5	3.4	2.8	1.1
ental disorders	6.3	11.0	7.8	4.5	2.8
Mental illness and nervous trouble	4.8	3.4	7.4	4.3	1.9
Mental retardation	1.2	7.5	.1	---	.1
rvous system disorders	5.2	11.9	3.3	4.7	3.7
Epilepsy	1.0	5.1	.2	.3	---
Multiple sclerosis	.6	.4	1.2	.4	.1
Paralysis	1.0	2.8	1.2	.6	---
igestive disorders	7.2	2.4	3.5	7.8	6.7
eoplasms	1.7	.5	1.6	2.1	2.3
rogenital conditions	2.5	2.8	3.6	2.1	1.6
iabetes	2.7	2.0	1.3	3.5	4.8
isual impairments	2.4	5.1	1.9	1.7	2.8
Other and unspecified conditions	4.9	10.2	5.6	3.3	2.9
Functional limitations					
Total percent	100.0	100.0	100.0	100.0	100.0
No loss 1/	26.7	39.7	29.0	20.3	19.7
inor loss	28.7	18.2	30.2	31.7	30.5
oderate loss	19.5	15.8	20.0	20.2	22.7
Severe loss	8.8	3.9	[illegible]	11.4	12.3
unctionally dependent	16.2	22.5	14.0	16.4	14.7

See footnote at end of table.

(Treitel, 1972)

TABLE 3 (cont.)

--Age at onset of disability by diagnostic condition and functional limitation: Percentage distribution of disabled and severely disabled noninstitutionalized adults aged 18-64, spring 1966--Continued

Diagnostic condition and functional limitation by severity of disability	Total	Age at onset of disability			
		Under 18	18-34	35-54	55-64
SEVERELY DISABLED					
Number (in thousands)	6,100	848	1,606	2,550	957
Diagnostic group and conditions					
Total percent	100.0	100.0	100.0	100.0	100.0
Musculoskeletal disorders	25.2	13.1	30.2	23.8	17.4
Arthritis or rheumatism	12.3	1.8	12.3	15.7	11.0
Back or spine	6.9	3.9	[illegible]	7.9	3.7
Impairment of limbs	3.3	5.4	3.6	3.3	1.2
Cardiovascular disorders	25.8	11.8	14.5	20.7	[illegible]
Heart trouble	11.8	2.6	6.7	13.3	23.1
High blood pressure	6.2	.7	3.4	7.0	10.4
Respiratory and related disorders	8.7	7.6	8.4	10.1	6.4
Asthma	2.7	5.5	1.5	2.7	1.5
Mental disorders	9.9	24.3	15.2	4.9	4.5
Mental illness and nervous trouble	6.8	[illegible]	[illegible]	[illegible]	[illegible]
Mental retardation	2.7	12.6	.2	.1	.1
Nervous system disorders	9.6	24.6	6.2	8.1	6.1
Epilepsy	1.6	9.4	.5	.3	.1
Multiple sclerosis	.6	.7	.9	.6	.2
Paralysis	1.6	3.8	2.5	1.1	.1
Digestive disorders	5.5	[illegible]	8.7	5.0	6.7
Neoplasms	2.7	1.1	2.6	3.1	3.1
Urogenital conditions	2.8	2.1	3.5	2.3	2.3
Diabetes	3.0	.9	1.5	3.2	6.2
Visual impairments	2.5	3.0	3.6	1.8	2.3
Other and unspecified conditions	4.3	11.1	5.6	2.8	1.2
Functional limitations					
Total percent	100.0	100.0	100.0	100.0	100.0
No loss 1/	13.7	18.8	18.1	9.3	[illegible]
Minor loss	25.1	16.7	27.0	26.9	25.0
Moderate loss	19.4	9.9	17.9	21.2	24.5
Severe loss	12.2	6.8	9.8	14.9	13.2
Functionally dependent	29.6	47.7	27.2	27.7	23.6

1/ No loss in capacities for physical activity, mobility, or self-care.

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Mr. **Ottinger.** Would you have any objection to having that included?

Mr. **Humphreys.** My preference would be, Mr. Ottinger, to at this time to hold the line, as I suggested in my testimony, on either including any specific disability or in broadly expanding it to include all disability categories, because I think that we, at least from my standpoint in the Rehabilitation Services Administration, are only beginning to really look at the policy implications of doing that sort of thing in the context of our entire effort on behalf of the disabled population and coordinating all programs for the disabled.

Mr. **Ottinger.** So that you do not feel you can support at the present time S. 2600.

Mr. **Humphreys.** At the present time, no.

Mr. **Ottinger.** S. 2600 does provide almost double the resources, however. If we were to adopt S. 2600, do you have any feeling as to the adequacy of these resources which are authorized?

Mr. **Humphreys.** I can only suggest to you the scope of the problem that we encounter in providing services to the disabled population 1 in 10 or 1 in 20. A doubling the dollar amounts could, of course, double the population served, presumably. The need is very great. I cannot say it is a bottomless pit but there is a great demand and great need for services to service the disabled population.

Mr. **Ottinger.** Thank you, Mr. Chairman.

Mr. **Rogers.** As I understand it, you are supporting a 2-year extension.

Mr. **Humphreys.** Yes.

Mr. **Rogers.** You say you do not want too many changes right now until you see how things work out. I am wondering, should we not consider something about planning requirements on a longer cycle than annually?

Mr. **Humphreys.** We have under consideration, and hopefully will have successfully concluded within the Department, a request to limit the need for annual State plans.

Mr. **Rogers.** Incorporating it in the overall plan.

Mr. **Humphreys.** The overall plan for the Department now in conjunction with the hoped-for limitation on reporting requirements is to provide for State plan submission once every 3 years. Hopefully, we will be able to do that within HEW for all programs and provide only annual updating where it is needed.

Mr. **Rogers.** Why don't we just provide it in the legislation?

Mr. **Humphreys.** That, of course, would be your prerogative. I do not think the Department would object to that.

Mr. **Rogers.** What about encouraging deinstitutionalization?

Mr. **Humphreys.** We are currently within the Department very seriously and very energetically looking at problems of deinstitutionalization.

Mr. **Rogers.** Have we studies on it?

Mr. **Humphreys.** There have been many studies on it, sir.

Mr. **Rogers.** Thousands probably. What is the conclusion?

Mr. **Humphreys.** We definitely ought to encourage it. At the same time we need to provide for alternatives in community living. We are in the process now of developing agreements with the Department of Housing and Urban Development on community-based facilities and transitional living arrangements, congregate living.

Mr. Rogers. Then you support doing more about deinstitutionalization.

Mr. Humphreys. Indeed, yes.

Mr. Rogers. We may write something there. Should we require some standards for university affiliated universities?

Mr. Humphreys. We do have performance criteria which we are studying now. Specific standards I would recommend against until we have the study on performance standards established.

Mr. Rogers. How long is that going to take?

Mr. Humphreys. We expect to have that by 1980.

Mr. Rogers. We cannot wait that long. Suppose we direct you to issue standards in 6 months, could you do it? You have done the study.

Mr. Humphreys. The study has begun.

Mr. Rogers. Don't we know generally what the standards ought to be? You have been working on this program for how long?

Mr. Humphreys. I think probably in general we know what the standards need to be.

Mr. Rogers. Do you have to prolong this until 1980? We have to get this program moving. Could you do it in 6 months?

Mr. Humphreys. Let me have Mr. Lynch respond to that.

Mr. Rogers. It probably could be done, could it not?

Mr. Lynch. It could be done better in 2 years.

Mr. Rogers. Of course. Thank you.

Now, in your budget, I notice you increased the amount requested for State formula grants, but you have kind of offset that with a decrease in project grants. Why?

Mr. Humphreys. That was done on the basis that many of our special project grants can really better be translated to the basic State grant program and the funds can be better used on a formula basis.

Mr. Rogers. Will you let us have for the record specific examples of what you plan to transfer and why you should have a decrease in the special project budget?

Mr. Humphreys. We will, yes.

[The following information was received for the record:]

In FY 1979 DDO will increase the formula grant allocation by $16.822M. ($14.010M from the Special Projects Section and $2.812 new money)

The rationale for this is that since special projects have been largely local service demonstrations they could just as easily be done through the State Councils. The DDO has received negative comments on the relative imbalance of the special project allocation.

In fiscal year 1977:	*Millions*
Projects of national significance	$5.9
Special projects	12.5
While all States totaled	30.0

This move redresses the balance.

Mr. Rogers. As to your expansion of definition, I understand the Commission wrote majority and minority reports on this.

Mr. Humphreys. Yes.

Mr. **Rogers**. How many additional persons is it estimated would be added to the coverage if it is broadened?

Mr. **Humphreys**. Depending on how it was broadened——

Mr. **Rogers**. As represented by the Commission.

Mr. **Humphreys**. I understand it would be somewhere on the order of one third.

Mr. **Rogers**. A 50-percent increase? And what would be the characteristics of these persons generally?

Mr. **Humphreys**. They would be individuals who had substantial impairments to their functioning in three or more major life activities. They would be people whose disability was manifested prior to age 22.

Mr. **Rogers**. Both of them recommended going to age 22.

Mr. **Humphreys**. Yes.

Mr. **Rogers**. Minority and majority.

Mr. **Humphreys**. That is right.

Mr. **Rogers**. Do you disagree with that?

Mr. **Humphreys**. I personally have not really come to a conclusion on that yet.

Mr. **Rogers**. It must be pretty good if both majority and minority think it is pretty good. I do not see any disagreement.

Mr. **Humphreys**. Not among those——

Mr. **Ottinger**. I do not see any logic to that. It apparently was not addressed. It was just assumed.

Mr. **Humphreys**. I think it is more than an assumption. The underlying reason behind that is that the concept of developmental disabilities is one which occurs during the developing years. Presumably those years go up to the age of 21, the majority. But physiologically and every other way, at least to our knowledge, that year is 21 or 22.

Mr. **Rogers**. Are their service needs similar to those of the currently covered population?

Mr. **Humphreys**. Yes.

Mr. **Rogers**. So you do not have any problem with that.

Mr. **Humphreys**. We do not have differentiation in services.

Mr. **Ottinger**. As I understand it, cerebral palsy can be contracted as a result of an accident during adult years. You said before there would not be a substantial population added but for those people who are affected, it would be extremely important. Would there be any problem with our eliminating that age 22 limitation?

Mr. **Humphreys**. You do make a good point. Of course, there could be other cases where the traumatic result of an accident, for example, results in a manifestation of epilepsy or mental retardation, or at least diminished mental capacity from brain injury. So your point is well taken.

This population under this definition where there is an age limit would not be considered within the scope of the developmentally disabled.

That raises another policy issue which, I think, we need to address and why, among other things, we are asking for an additional 2 years to study it. We need to know precisely what must be done for our severely disabled population in the overall context of our service delivery system.

I think that the ideas behind the developmental disabilities program have been excellent for that population. I think that it certainly coincides with my own idea of the need for better coordination and for the marshaling of resources to focus on the needs of this targeted population.

But I think we need to reflect on what DD has done over the past several years and where we are going in the future and what needs to be done in this area.

One of the major efforts that I think is absolutely necessary is the development of a national policy on disability: What do we need as a Nation in developing a program for our disabled population?

Mr. **Rogers.** Let me ask you to comment on the approach which is an alternative approach being considered by the Senate, which would establish service programs for the severely disabled. Would the interests of the developmentally disabled population receive sufficient attention under a general program for the disabled as proposed there or would they tend to be overlooked?

Mr. **Humphreys.** My assumption is, and I do not know if it is a valid assumption or not, that the State DD councils and the mechanisms that are already in place would continue. Having been established, they would continue to be supported, by virtue of the fact that they have enjoyed in many cases a good reputation. In some cases they have not, however, and in those cases, possibly they would suffer.

Again, I point out that S. 2600 would no longer fund or specifically recognize in the legislation State planning councils.

Mr. **Florio.** I want to amplify on that point. Should the Senate approach be enacted, would we not find the developmentally disabled competing among themselves for money since funds would not be earmarked specifically for them? That sounds very much like the old block grant approach. We provide the moneys and then we have everyone scurrying around to grab off as much as they can and, unfortunately, we will find some people who are left out.

I have some apprehensions that it will be the developmentally disabled who will be left out.

Mr. **Humphreys.** That, of course, is potentially the case. We are in the process of developing some legislative initiatives in some other areas. Among those are independent living rehabilitation services. We are also developing an initiative with respect to community-based technical assistance to provide information through technical information resource centers, which would in turn be a resource in a region to individual communities to develop their own capacity to serve their disabled residents in many ways.

Those are two things that are in some ways reflected in title II of S. 2600. We think those are good ideas but we can not at this point support the whole approach of title II.

Mr. **Rogers.** Do you feel comfortable that we know what a service program for the disabled, as so proposed, should look like?

Mr. **Humphreys.** I do not think we know that wholly yet. We have developed a conceptual framework—excuse me if I am too long-winded—we have developed a conceptual framework for at least the beginning of a national policy on disability, which considers a continuum of care, from the least severely disabled to the most severely disabled, from community-based services through independent living rehabilitation services, to vocational rehabilitation, to institutionalization.

We also need to impact on five levels of concern, from prevention, to amelioration, to maintenance, to habilitation, to rehabilitation.

Mr. ROGERS. When will you present that to the Congress?

Mr. HUMPHREYS. I cannot guarantee that as a concept I can present to the Congress. I have, myself, developed a concept paper internally, which I would be happy to share with you.

Mr. ROGERS. I think that would be helpful if you could furnish that to the committee.

I think the point you make, Mr. Florio, is very good. We need to look at this carefully.

Now, as I recall, you praised the DD councils and feel that they do play an important role.

Mr. HUMPHREYS. I believe so.

Mr. ROGERS. Have you any suggestion on how we can make them more effective? Are they adequately staffed now or should we set some minimum standards?

Mr. HUMPHREYS. Quite frequently they are not adequately staffed. Of course the amount of money available to the State councils is quite limited, and the amounts appropriated have been considerably below the amount authorized.

Mr. ROGERS. Can you give us a list of those who are not adequately staffed?

Mr. HUMPHREYS. We will do that.

[The following materal was received for the record:]

Full-time or Part-time Professional Positions Funded by DD

STATE AGENCY
Contract
Personnel
Personnel
on Loan

Figure 1: Continuum showing polar extremes of employment configurations of DD professionals.

On the one extreme to the left, the Council hires the DD professional(s) on contract. The professional is hired by the Council and reports solely to the Council. The other end of the spectrum on the right, is the situation in which the Administrative Agency employs the professional and "loans" him or her to the Council. The professional reports to the agency but serves the needs of the Council. There are various employment configurations along this continuum and some are still being worked out.

Table 1 shows that at present there are 137 full-time or part-time professional positions funded in Developmental Disabilities in the United States at the present time. There are 14 states which have only one professional staff position. There are 17 states which have two professionals reporting to the DD Council. The majority of these states have a Director or Coordinator and a Planner. There are 34 states that have one or more Planners on staff.

There is a great variety of professionals with specific skills reporting to DD Councils throughout the country. The titles of the individuals are recorded on Table 1.

TABLE 1. STAFF PATTERN FOR D.D. COUNCILS IN THE 54 STATES AND TERRITORIES BY NEW REGION

STATE/TERR.	Total No. Prof. Staff	POSITION: PROFESSIONAL					CLERICAL
		Director	Planner	Other	Other	Other	
REGION I							
Connecticut	3	1		Pub.Inf.Off	Res.Ana		1
Maine	2		1	Res.Asst.			2
Massachusetts	6	1	5				2
New Hampshire	3	1	1	Res.Asst.			
Rhode Island	3	1		Res.Asst.(2)			1
Vermont	1	1					1
REGION 2							
New Jersey	4	1	1	Comm.Spec.	Adm.Scrip		2
New York	3	1	1	Prog.Coord.			2
Puerto Rico	3	1	1	Accountant			2
Virgin Island	0						
REGION 3							
Delaware	2	1	1				1
Dist. Columbia	1	1					1
Maryland	4	1	1	Asst.Dir.	Dir.Advocacy		2
Pennsylvania	5	1	2	Pub.Inf.Off	Grants Mgr.		1
Virginia	3	1	1	Asst.Dir			1
W. Virginia	3	1	1	Pro.Spec.			1
REGION 4							
Alabama	2	1		Adm.Asst.			
Flordia	6	1	2	CP Const.	EPSConst.	Prog.Dir.	1
Georgia	4	1	1	Researcher	Comm.Const.		1
Kentucky	1		1				1
Mississippi	1		1				
No. Carolina	2	1	1				
So. Carolina	1	1					1
Tennessee	1ft,4pt	1(ft)	1(pt)	3Prog.(pt)			

STATE/TERR.	Total No. Prof. Staff	POSITION: PROFESSIONAL Director	Planner	Other	Other	Other	CLERICAL
REGION 5							
Illinois	7	1	5	Dir.Advo			3
Indiana	1	1					
Michigan	5	1		Coord.	3 Const.		
Minnesota	4	1	3				3
Ohio	4	1	2	(1)Program			2
Wisconsin	2	1		Evaluator			1
REGION 6							
Arkansas	1	1					
Louisiana	2	1		Prog.Asst.			1
New Mexico	2	1	1				1
Oklahoma	1		1				1
Texas	1		1				1
REGION 7							
Iowa	4	1	3				
Kansas	2	1		Evaluator			
Missouri	2	1	1				1
Nebraska	4	1	1	Pub.HealthEd.	Spec.Asst.		1
REGION 8							
Colorado	3	1	1	Ast.Staff Dir			
Montana	2	1	1				1
No.Dakota	2	1	1				
So.Dakota	2	1		Asst.Dir.			1
Utah	2	1	1				
Wyoming	1	1					

TABLE 1 (continued)

STATE/TERR.	Total No. Prof. Staff	POSITION: PROFESSIONAL					CLERICAL
		Director	Planner	Other	Other	Other	
REGION 9							
Arizona	2	1	1				
California	4	1	3				1
Guam	1	1					
Hawaii	2		1	Advocacy Dir.(pt)			
Nevada	1	1					1
REGION 10							
Alaska	2		2				1
Idaho	1	1					2
Oregon	1	1					1
Washington	2		1	Advocacy Dir.			2

(1 Flordia Staff under Contract to DD Council

(2 One of the 5 Planners is Director of Planning .

(3 Reg. VI in response to new legislation is in the process of designating one staff member as solely responsible to the Council.

(4 Louisiana is awaiting civil service approval of the DD Program Assistant Position.

(5 Alaska is in the process of defining tasks and Responsibilities for these professionals.

Mr. Rogers. Do we need to clarify the relationship and responsibilities of the State councils and State agencies?

Mr. Humphreys. I do not quite know how to answer that question. Let me have Mr. Lynch speak to that.

Mr. Lynch. The question is: Do we need to clarify the role between the State agencies and State councils?

Mr. Rogers. The relationship and the responsibilities of the State councils and the State agencies.

Mr. Lynch. I think they were clarified in the last legislative go-round where the responsibility for design implementation rests with the State agency personnel and staff.

Mr. Rogers. Do you think that is sufficient?

Mr. Lynch. I think it is working out well, sir.

Mr. Florio. Would the gentleman yield on the question?

Mr. Rogers. Certainly.

Mr. Florio. It is my understanding that the result in a number of States varies tremendously; and in some instances, my own State, the council—we think it is desirable—has gotten to the point where it has become the leader.

In other States, the council is an advisory body, and the agency makes policy after they consult with the council. So, although the rules are fairly standard, what happens in effect may very well gravitate to the personalities involved. Maybe that is desirable.

Could I ask for some verification as to whether my understanding is correct, that in some States it is the agency that is determining policy, and in other States the council, notwithstanding the advisory role of the council to determine policy?

Mr. Humphreys. I think your perception is correct, Mr. Florio, I agree that probably in many cases it is a matter of personalities rather than the specifics of the law.

Mr. Florio. Is it desirable or not desirable?

Mr. Humphreys. I think we have to determine that. I think we have to determine on a State-by-State basis how these programs are being effectuated, and where there are deficiencies we should target our resources and attention on those that are not working the way we hope they would.

Mr. Florio. Thank you.

Mr. Rogers. Now, you seem very supportive of protection and advocacy systems.

Mr. Humphreys. Very much so.

Mr. Rogers. Already we are at the authorized level. Do we need any increase in authorization?

Mr. Humphreys. As I stated, Mr. Chairman, we have only just begun to put those systems into operation. The $3 million was a starting point. I think that probably as States develop their capacity, assuming that there is an interest on the part of the States in doing so—and I think there will be, not only for the developmentally disabled population but for all disabled individuals—there will be a great interest in expanding and improving and strengthening.

Mr. Rogers. You say you need additional authorization, in effect.

Mr. Humphreys. I think the States could very well use additional funds from some source.

Mr. **Rogers**. On the deinstitutionalization effort, what are your plans on this, and can we strengthen our legislation to address this issue more effectively?

Mr. **Humphreys**. The deinstitutionalization?

Mr. **Roger**. Yes.

Mr. **Humphreys**. Of course the role of the developmental disabilities program in deinstitutionalization is relatively small. We have a panoply of HEW programs that are involved and concerned with deinstitutionalization, the problems of long-term care, nursing homes and intermediate care facilities, a wide range of people who are institutionalized who are not directly and specifically related to the DD program but which we must definitely address, both as a department and as a government.

Mr. **Rogers**. Have we not specifically tried to target in on the DD population? As I recall, that was the thrust of the last legislation.

Mr. **Humphreys**. Yes. There is a requirement for 30 percent of the funding in the developmental disabilities program to be directed toward deinstitutionalization.

Mr. **Rogers**. What has happened?

Mr. **Humphreys**. There have been efforts toward deinstitutionalization.

Mr. **Rogers**. How successful have they been?

Mr. **Humphreys**. I think in some cases they have been more successful than they perhaps should have been. The reason I say that is that there are in many cases no alternatives for the people who have been released from institutions. They have been actually dumped on the streets in some cases.

Mr. **Rogers**. What will you propose on deinstitutionalization?

Mr. **Humphreys**. I cannot project it at this point.

Mr. **Rogers**. What is your own thinking?

Mr. **Humphreys**. My own thinking is most tentative at the moment.

Mr. **Rogers**. I understand that. What is it?

Mr. **Humphreys**. I certainly believe that for myself we need to develop a greater resource capability in the development of residential housing.

Mr. **Rogers**. How will we do that?

Mr. **Humphreys**. We can do it through, I think, joint agreement between HUD and HEW.

Mr. **Rogers**. Have you had negotiations with HUD on this?

Mr. **Humphreys**. Yes.

Mr. **Rogers**. Are they agreeable?

Mr. **Humphreys**. On a tentative basis they are setting aside some $5 million in section 202, and using section 8 funds which will provide for transitional living arrangements. We are coordinating with the Department in providing services to the population that are released.

Mr. **Florio**. Would the gentleman yield?

Mr. **Rogers**. Yes.

Mr. **Florio**. You say they are setting aside that amount of money. Is that set-aside over and above the moneys that already have been allocated in the budget area allocations for sections 8 and 202?

Mr. HUMPHREYS. I frankly do not know the source of that. I can provide that for the record.

Mr. FLORIO. Well, I think that it is very significant. The moneys set forth for sections 202 and 8 already are deficient for existing needs. If we are going to set aside a portion of that allocation, we are not really saying anything at all. If there is a contemplation that we are going to ask for and request additional moneys over and above what we have now, that is one thing. If we are just going to get the statement that we are going to set aside moneys from an already deficient amount, then I regard that as a non-answer from HUD.

Mr. HUMPHREYS. I cannot at the moment give you a better answer but I will attempt to provide one for the record.

Mr. FLORIO. Thank you very much.

[The following information was received for the record:]

HUD 202 PROGRAM[1]

Fiscal Year 1979—$750 was originally required for new starts in construction/renovation of group homes for handicapped and congregate housing for the elderly.

In light of HUD's concern for the deinstitutionalization of the developmental disabled and the mentally ill, and the need for community based alternatives for the physically handicapped (non DD $50 million more was added to fiscal year 1979's 202 program request. $5 million is earmarked in for use by the Mentally Ill and $50 million in fiscal year —— will be for DD and physically handicapped. None of the above has been finally approved.

Mr. ROGERS. This would be one approach, to go through HUD. What else are you planning on deinstitutionalization?

Mr. HUMPHREYS. I think that certainly we need to provide a "gatekeeping" function.

Mr. ROGERS. What?

Mr. HUMPHREYS. "Gate-keeping" to insure that people are appropriately placed and those who are inappropriately placed are released. That is another area that we are beginning to develop in conjunction with our whole deinstitutionalization process.

I think it is a vital capacity which the States and sub-State units do not have, to be able to have an impact on institutions within their localities.

Mr. ROGERS. Do you expect to present any legislation before the May 15 deadline?

Mr. HUMPHREYS. We will have legislation to amend the Rehabilitation Act. We will also have, as I suggested, a proposed bill to extend for 2 years the Developmental Disabilities Act.

Mr. ROGERS. To do what?

Mr. HUMPHREYS. To extend the DD Act.

Mr. ROGERS. What are you recommending in the other area?

Mr. HUMPHREYS. In the Rehabilitation Act? I alluded to two of the major initiatives that we had proposed. The third is an expansion of employment opportunities for the severely disabled. There are several areas within that.

We would provide an expanded project with an industry program, which is a cooperative arrangement between RSA and industry to provide for a specific number of jobs and job placements and job training for disabled individuals.

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[1] Information from Dave Williamson's office, Office of Independent Living, HUD.

Mr. Rogers. Why aren't you recommending the HUD program in this program and why aren't you recommending the gatekeeping approach here too?

Mr. Humphreys. We had initially thought of bringing forward the gatekeeping concept within this legislation or within the community-based services part of the Rehabilitation Act extension amendments. We believed, however, that it was perhaps premature to do that, thinking that we best have the entire package and the entire departmental approach to the whole matter of deinstitutionalization rather than approaching it piecemeal.

Mr. Rogers. You have that for the vocational programing?

Mr. Humphreys. No.

Mr. Rogers. But you are going to recommend it for that?

Mr. Humphreys. We may. I cannot say that with certainty yet.

Mr. Rogers. You are thinking about doing it, I understand.

Mr. Humphreys. We in RSA are. I am not sure we can get it through the Office of Management and Budget.

Mr. Rogers. Why is it you want to pick out the vocational program and not help the DD on gatekeeping and on the deinstitutionalization by the HUD program?

Mr. Humphreys. I perhaps misspoke myself. What I meant was that in establishing this gatekeeping function, it would be an amendment to the Rehabilitation Act. As I am suggesting, rehabilitation is expanding in concept. It is no longer just vocational rehabilitation, but hopefully we will include independent living rehabilitation services as well. We are bringing the Developmental Disabilities Office within the organizational structure of RSA.

That expands it yet to another dimension in terms of both age and in range of disabilities and kinds of services that should be provided.

Mr. Rogers. Why should that not be enacted within this program as well, is what I am asking? Why should we wait?

Mr. Humphreys. I do not know that it matters which act is amended to provide for that.

Mr. Rogers. Will you let us have your recommendations on that, the legislative recommendations, so that we can consider whether to put them in this? That will be helpful.

Mr. Humphreys. Yes.

[The following information was received for the record:]

Mr. Humphreys has informed the Committee that a copy of the administration's proposals on independent living will be furnished as soon as all clearances have been made.

Mr. Rogers. Now, on this evaluation system, as I recall in the 1975 legislation, we required the administration to develop a system for evaluation of services provided to the developmentally disabled. It was supposed to be available in 1977 so that the States could begin implementing it.

Now, in the legislation we are considering today, you have had to postpone that time table evidently. You have indicated, though, that you are now substantially complete in the consideration of this. What have the results of the study been and what particular problems would there be?

Mr. **Humphreys.** The approach has been one of several segments. We believe that perhaps the Congress was a bit ambitious on our behalf in providing such a stringent time table for us to keep in developing that.

Mr. **Rogers.** Two years?

Mr. **Humphreys.** Yes. A number of different steps had to be taken in sequence in order to fully develop the evaluation system, the initial part of which was the determination of what was required in terms of privacy and confidentiality. At the time that was adopted, the Privacy Act was only in its beginning stages of implementation and we had no precedent and not much assistance to determine how we should proceed in protecting the confidentiality of the clients involved.

So, a study was undertaken to determine the parameters of what could and should be done, through a survey of the socio-legal aspects of confidentiality and privacy. Subsequent to that then—and that was completed, as I recall in 1976—the effort was underway to provide a model State code and development of regulations on the part of the Federal Government in reaction to that study that was done on privacy and confidentiality.

That was completed in September of last year. Then, specifications had to be developed on the developmental disability assessment instruments to be used in such an evaluation system and design specifications for a comprehensive evaluation system.

I would commend those who preceded me on the thoroughness with which they approached the task here. It appears to me that with the carefulness and the consideration of all the various factors involved, the comprehensive evaluation system will be a good and complete system, once it is in place.

Mr. **Rogers.** When will that be?

Mr. **Humphreys.** My understanding is that in October of 1979, the study and model will have been completed so that the States may implement it by October 1982. That seems a long way away.

Mr. **Rogers.** In other words, you are taking this study and now are studying how to use the study? Is that about it?

Mr. **Humphreys.** Let me undertake, Mr. Chairman, to determine whether and in what ways that time schedule might be compressed. I agree it does seem overly long.

Mr. **Rogers.** Would you let us have that for the record.

Mr. **Humphreys.** I will.

Mr. **Rogers.** I think it needs to be speeded up.

[The following information was received for the record:]

TIMETABLE FOR COMPREHENSIVE EVALUATION SYSTEM

Under our present schedule, the specifications for the system will be ready for dissemination to the states by October, 1979. The timetable we have been following subsequent to that is the one prescribed in Public Law 94–103. That is, that the states have six months to develop plans for implementing the system and, based on the approval of those plans, two years to implement and operationalize the system.

Six months to develop plans is a reasonable expectation, and important, since it is through the plans that we can ensure that the systems developed by the states meet the specifications we have so carefully designed. The two-year implementation phase may be somewhat misleading. We have projected that within two years the evaluation system will have reached every developmentally disabled persons in the system, including initial individual assessments and subsequent measures of developmental progress. That is, within two years, the system would be fully operationalized. It does not mean that the system won't be implemented until 1982.

In fact, we have estimated that in most cases, the systems will be operating successfully after one year. The purpose of the second year is to evaluate the states' efforts and provide technical assistance in resolving any problems they may be confronting. Since implementation is required for the states to receive their formula grants, the intent was to ensure that deadlines in initiating this entirely new activity were not punitive.

Projected Implementation Schedule:

October, 1979	Specifications and guidelines disseminated to the states.
April, 1980	Implementation plans due from the states.
June, 1980	States begin implementing approved plans.
April, 1982	Evaluation systems are fully operational in all states and territories.

Mr. FLORIO. Mr. Chairman, I have just one or two questions.

With regard to the Senate approach including generally disabled people in a larger category, what are the major groups that would then be encompassed in the category of generally disabled who would not be in the category of developmentally disabled?

Mr. HUMPHREYS. The intent, as I understand it, of title II of the Senate Bill is to include all individuals who are severely disabled. That, of course, ranges throughout all disabilities, mental illness, physical disabilities of many and various kinds. We could, of course, go through the list.

Mr. FLORIO. Can you give me some rough numbers as to what the category of DD would be as contrasted with what this new, larger classification would entail?

Mr. HUMPHREYS. As I indicated and as the chairman indicated, the total DD population from the least severely disabled to the most is about 10 million. The substantially handicapped development disabled are about 2 million.

Now, the best estimate we have of the total population of disabled citizens in the United States is roughly 35 million from least severe to most severe. The total number of severely disabled persons of whatever category is somewhat more than 10 million.

So, the DD population in that construction, who are most severely disabled, would be roughly one-fifth of the total disabled population. So, we have expanded the construction of that sum five times.

Mr. FLORIO. What are the corresponding amounts of money that have been talked about for expanding this population to be serviced? Do you have five times the amount of money being authorized?

Mr. HUMPHREYS. Not initially, as I recall. The first year's authorization is something on the order of $100 or $110 million under title II. There are a couple of categories that provide for separate authorizations but that is, I think, the primary program.

Mr. FLORIO. My apprehension seems to be well founded, that we are going to expand the group service but we are not going to expand the money comparably and, as a result, we are going to have more intensive competition for the lesser amounts of money.

Mr. Humphreys. That could very well be the result.

Mr. Florio. On the housing question, you represented to me that in 1977 HUD provided moneys for only 56 group homes for handicapped people under the 202 loan program. Has there been any discussion in these conferences between HEW and HUD as to the number of homes that could be financed under the sums that are being talked about?

Mr. Humphreys. They probably have gotten into that kind of detail. I have not been a party to that particular discussion. I do know that there are plans underway on a demonstration basis to provide housing from HUD and services from HEW for 400 chronically disabled, mentally ill individuals, to deinstitutionalize those individuals in group homes.

Mr. Florio. Under the 202 program, it is my understanding that the applicants would for the most part be nonprofit corporations.

Mr. Humphreys. I cannot speak to that.

Mr. Florio. I have no further questions.

Mr. Rogers. Thank you very much. We appreciate your presence here today. If you could let us have the information that members have requested, it would be appreciated.

Mr. Humphreys. We will do so.

Mr. Rogers. Do you have further questions, Dr. Carter?

Mr. Carter. Yes, Mr. Chairman.

Has there been useful research in connection with activities of university-affiliated facilities?

Mr. Humphreys. Excuse me, Sir. I did not hear the first part of the question.

Mr. Carter. Has there been much useful research in connection with activities of university-affiliated facilities?

Mr. Humphreys. Much of what the UAF does is training of professionals, parents and consumers. The research effort, at least as far as the developmental disabilities portion of the funding is concerned, I cannot speak to. DD funds are a relatively small proportion of the total support for UAF's.

Mr. Carter. Have you seen one?

Mr. Humphreys. Yes, I have.

Mr. Carter. How many do we have?

Mr. Humphreys. There is a total of 37 university-affiliated programs which are supported in part by DD and 46 overall.

Mr. Carter. What was unusual about your observation of the University-Affiliated Facilities?

Mr. Humphreys. I do not know that anything was particularly unusual about it.

Mr. Carter. Definitely unusual.

Mr. Humphreys. They did not have any dyslectics.

Mr. Carter. You could see them but they could not see you when you were observing.

Mr. Humphreys. I see. In the training process.

Mr. Carter. Thank you.

Mr. Rogers. Thank you very much.

[Testimony resumes on p. 104.]

[The following concept paper was received for the record:]

A CONCEPT PAPER BY ROBERT R. HUMPHREYS

Being Disabled in America

A short overview of the problems and needs of

disabled citizens, and some approaches to

solutions.

I. Introduction

Disabled individuals represent a sizeable minority of the Nation's total population. The needs of this population have been addressed in an ad hoc, piecemeal fashion, without an overall strategy, policy, or plan to use as the basis for service delivery to meet all or a large percentage of those needs. As a result there are huge service gaps and unmet needs, and there is no coordinated comprehensive network for the provision of services.

This paper does not purport to address all the needs of this important segment of our society, for they are many and complex. It does indicate, to the extent that such information is currently available, the scope of the problems and unmet needs. It strongly recommends some bold new approaches in legislation and administrative action that can bring more rationality, coherence, and efficiency to the Federal government's efforts to impact favorably on the lives of the handicapped citizens of this country, and begin to build the capacity for providing a nation-wide service network for disabled people.

The immediate purpose of this paper is to provide justification for a series of major legislative initiatives and possible administrative changes.

II. Summary of Facts and Conclusions

1. The population of chronically disabled people in America is estimated variously at 25 to 35 million, or between 10 and 15% of the total United States population. Of these, more than 10 million may be categorized as severely disabled.

2. Disability may be defined as an inability to perform some key life functions, as contrasted with an impairment (a residual limitation resulting from congenital defect, disease, or injury), or a handicap (environmentally imposed impediment to an individual's ability to work or travel).

3. The population with whom we associate the term disability include those who are mentally retarded, mentally ill, and physically disabled. People in the latter category have wide and varying types of disability, including paraplegia, arthritis, sensory deficits (blind, deaf, deaf-blind), epilepsy, heart disease, cancer, stroke, amputations, multiple sclerosis, cerebral palsy, muscular dystrophy, osteogenesis imperfecta, spina bifida, cystic fibrosis, chronic respiratory dysfunction, and many others.

4. There is a total spectrum of disability levels. People with disabilities may live and function with relative ease and normality, or they may be homebound or institutionalized.

5. Service programs exist for the benefit of disabled individuals. Some of these, such as vocational rehabilitation and comprehensive medical rehabilitation centers, attempt to meet many of the needs through direct and indirect means. Other programs such as developmental disabilities, attempt to leverage a fairly broad range of services for a discrete segment of the disabled population. Others provide services for specific purposes but are not specific to disabled people. These include food stamps, income maintenance, and medical service programs, for example.

6. Community based services especially tailored to the needs of disabled individuals are badly needed, but are not widely available.

7. Comprehensive services to individuals who are severely disabled and do not have a vocational goal or anticipated vocational outcome, exist only in widely scattered demonstration programs.

8. There is no comprehensive program to provide employment for disabled people who wish to work. Training services and preparation for employment are provided, along with other specially tailored services, through vocational rehabilitation programs, but placement services are inadequate, and followup for job adjustment and satisfaction are almost nonexistent.

9. There is no nationwide network of comprehensive services to meet the wide range of needs of all disabled citizens. Without such a network, these needs will not be fully met; deinstitutionalization cannot be accomplished on a large scale; services cannot be delivered with maximum efficiency, maximum effectiveness to disabled individuals, nor will the economic impact of providing services be reduced to the minimum.

10. We propose that planning be initiated for the construction of such a nationwide network of comprehensive services. A National Policy on Disability must be developed to eliminate conflicts in Federal programs and to coordinate policy and planning for those programs.

11. With the reorganization of the Office of Human Development Services and within it, the Rehabilitation Services Administration, a structural framework is established to begin to rationalize Federal programs for the disabled. RSA now includes the developmental disabilities program, will create an office of advocacy and coordination into which the Departmental coordinating unit, the Office for Handicapped Individuals will be placed. A broad new consumer oriented National Disabilities Advisory Council will be established, and a special unit to analyze and assess the cross-government recommendations of the White House Conference on Handicapped Individuals.

12. The proposals to amend and extend the Rehabilitation Act and the Developmental Disabilities Act and the Developmental Disabilities Act will fill four major gaps in the provision of services to people with disabilities, and will build capacities in communities, States, and the Federal government for developing a comprehensive service network:

    - Independent living rehabilitation services will be established, first on a limited scale through project grants, then comprehensively through a formula grant program.

    - Community-based information and technical assistance centers will be established in each region to assist local government in meeting the needs of disabled residents.

    - An expanded system of government-industry interaction to provide jobs to disabled people will be initiated, with national guidance and direction provided by RSA, which will plan and build a web of such interactions across the nation.

    - States will be given an opportunity to develop a gatekeeping capacity to prevent inappropriate institutionalization, to remove individuals from institutions, and to improve those institutions which continue to be required.

13. These legislative proposals are quite modest, and will not begin to meet the total need. They do represent a beginning, and a national commitment to provide a continuum of care for our disabled citizens. The network of services will be developed, through policy development, long range planning, and carefully monitored program expansion in future years.

III. Scope of the Problem: The Universe of Needs

Although numerous Federal programs are designed to provide services to disabled people, and though many of these are eminently successful in addressing a portion of the total need, there is no overall direction and no plan to meet the complex and interrelated needs of the disabled person as a total individual.

Who are the disabled? How are they defined, and how many people can be characterized as disabled?

Total population figures on the disabled have never been compiled. Questions included in the 1970 U.S. Census have provided some answers, as have various demographic studies. But no fully reliable data base now exists.

. Projections based on a New York study indicate that there are over 2,000,000 severely disabled individuals who are homebound.

. About 24,000,000 Americans have arthritis, of which some 5,000,000 are disabled, and of whom 475,000 are receiving Social Security Disability benefits.

. There are 250,000 to 500,000 adult Americans with multiple sclerosis.

. Some 13,000,000 Americans are hard of hearing, of which 1,800,000 are severely disabled by deafness, and of which an estimated 100,000 are low-functioning deaf.

. Over 5,500,000 individuals are mentally retarded. Of those, about 3,500,000 are substantially handicapped by retardation.

. More than 4,000,000 Americans have epilepsy, and 1,400,000 of these are substantially handicapped by this condition.

. At least 2,000,000 adults with severe, persistent psychiatric disabilities reside in their communities.

The following chart provides an estimate of the severely disabled population in America*:

Age	Number
Under 18	180,000
18 - 64	4,200,000
65 and over	3,900,000
Institutionalized (all ages)	1,787,000
Total	10,067,000

*Source: Urban Institute, July 1975

The Urban Institute, in a study conducted pursuant to section 130 of the Rehabilitation Act of 1973 (entitled "Comprehensive Needs Study of Individuals with the Most Severe Handicaps") alluded to the many definitions in use to describe the population at risk. The study recommended that the term impairment be used to describe a residual limitation resulting from congenital defect, disease, or injury. Disability describes an inability to perform some key life functions. A handicap occurs when the environment imposes impediments to the individual's ability to travel or work.

Overall, the total population of disabled individuals in America has been variously estimated at 25,000,000 to 35,000,000, which figures include varying degrees of chronic disability. An accurate data base is essential to our efforts to design the scope of a service delivery system for this population.

There are many parallels between the conditions and attitudes faced by disabled Americans today and those confronting the racial minorities in the 1960s. Inability to obtain employment, public attitudes toward disability, poverty, inadequate health care, and other forms of discrimination are as relevant to disabled people now as they were to blacks in decades past. It is hardly necessary to note that discrimination against racial minorities continues, although dramatic advances have been made in recent years.

Some statistical information compiled by the Social Security Administration is useful in beginning to portray a profile of disability in America.

The following ratios apply to totally disabled individuals in relation to non-disabled individuals:

- Hospitalization (men) - 4 times as often as non-disabled
- Days hospitalized - 3 times longer than non-disabled
- Cost of medical care - 3 times higher than non-disabled
- Median cost of care as a percent of income - 5 times as high as non-disabled
- Average income - half that of non-disabled

There are other expenses faced by disabled people that the "able-bodied" do not have. An electric wheelchair costs some $3,000 to $4,000, with annual maintenance costs of $1,200 to $1,600 - more than most automobiles. Interpreters for the deaf, readers for the blind, attendants for severe paraplegics, home health care, all represent continuing expenses for disabled people.

Other data help to fill out this disparaging picture. Only 30% of totally disabled men and 60% of totally disabled women have health insurance protection, compared with 90% of those who are not disabled. Fully 3/8 of totally disabled people - 37.5% have incomes, earned and unearned, below the poverty level. Seventy-six percent of totally disabled men and 87% of totally disabled women are not in the labor force; only 12% and 2%, respectively, work full time.

Education and disability are also interrelated. Nine percent of totally disabled persons have attended college, as opposed to 30% of those who are not disabled, while fully 44% of the totally disabled have an elementary school education or less, and only 13% of the non-disabled are in this category.

Although rates of marriage are comparable for totally disabled and non-disabled persons, one who is totally disabled is twice as likely as his non-disabled counterpart to be divorced or separated.

This information assists us in recognizing the devastating impact of disability on the individual and his or her family. Without major efforts to improve services and coordinate them, it is unlikely that these sad statistics will change dramatically in the future.

IV. ~~III~~. Pressures for Change

Because of the recognition of the massive deficits in meeting the needs of disabled people, the Congress took some positive initial steps to correct past deficiencies through enactment of Public Law 93-112, the Rehabilitation Act of 1973. Two earlier, more ambitious measures were vetoed by President Nixon.

Several of the provisions of that law became catalyst for change. Title V of the Rehabilitation Act contains four sections which are only now beginning to have nationwide impact. Section 501 requires affirmative action by the Federal government to hire, place, and advance in employment handicapped individuals. Section 502 established an Architectural and Transportation Barriers Compliance Board to monitor and enforce Federal agency and grantee adherence to standards established under the Architectural Barriers Act of 1968. Section 503 requires government contractors to have affirmative action programs to hire disabled individuals. Finally, section 504 prohibits discrimination solely on the basis of handicap by any individual or institution receiving Federal financial assistance.

With the 1974 amendments to the Rehabilitation Act came enabling legislation for the establishment of a White House Conference on Handicapped Individuals. That conference, held in May of 1977, attracted nationwide interest on the part of disabled individuals and generated the hope and expectation that government - Federal, State, and local - would become more responsive to their needs. Hundreds of recommendations for legislative and administrative change emanated from the White House Conference. Review and appropriate implementation of those recommendations are about to begin.

Public Law 94-142, the Education for All Handicapped Children Act requires that all handicapped children be provided a free, appropriate, public education. Deadlines for meeting this requirement are imposed.

These developments have generated new consumer involvement, advocacy, and even militancy. Public awareness of the needs of the disabled has been heightened. Citations are being issued by the Architectural and Transportation Barriers Compliance Board. A new Administration committed to insuring the rights of handicapped Americans, has taken office. Deinstitutionalization of mentally retarded and mentally ill persons is under active review. Court decisions expanding the rights of institutionalized persons are being rendered.

Adding to the complexity and the challenge of these factors are advances in medical and biomedical knowledge and technology. Persons with congenital defects or traumatic injury or disabling diseases who would have died a generation or two ago, are through these advances being sustained. An increasing number of older persons, with attendant disabilities in many cases, including arthritis, renal disease, retinitis pigmentosa, and many others, are adding to the problem. Recreational accidents and disabling automobile and motorcycle accidents are increasing the number of persons with spinal cord injuries and traumatic brain damage. Cancer, stroke, and heart disease continue inexorably to add to the list of disabled individuals.

It is clear that the pressures for change in our way of dealing with the disabled are increasing. How can we begin to deal with those increasing pressures, which are in the final analysis, merely reflections of need?

V. Proposed Structure for a Comprehensive Service System for Disabled Individuals

A. There is no system for the delivery of a continuum of services to disabled people in America.

There are scattered programs which, with varying levels of adequacy, address different needs of these individuals. Some of these are directed to the special needs of the disabled, such as rehabilitation services and SSDI. Others are not disability related, such as title XX and food stamps. Since there is no coherence, pattern, or plan relating to the provision of services the needs of the whole individual are nowhere considered, and as a result there are both major gaps in services and pervasive unmet needs.

In the absence of a comprehensive plan to meet those needs, it is a logical consequence that capacity is also lacking on the part of Federal, State, and local government, and in the private sector, to provide a full range of services to disabled individuals. In addition to the lack of capacity to meet needs, government and private funds have in past years been spent on facilities that are now perceived to be inappropriate. Other funds have been spent on services that are misdirected.

These deficiencies in policy, planning, services, and facilities all represent barriers to the full integration of the disabled into the mainstream of American society. Since these deficiencies have existed since the beginning of our nationhood, disabled individuals for the most part have been sheltered, and institutionalized. Because they are "different" from the able-bodied, they are all too often misunderstood and even feared.

Fear, misunderstanding, and a sheltered environment have resulted in a society that ignores the needs of this population. Barriers, not only physical but also attitudinal, are the legacy of these long generations of neglect.

The task for society, then, is to begin to correct these long standing inadequacies. Our mission is to provide a conceptual framework for their correction through a planned, comprehensive network for service delivery, and to begin to fill some of the gaps in services, service delivery capacity, and public awareness and attitudes.

B. The ideal structure for comprehensive service delivery would insure a continuum of service for all disabled individuals ranging from preconception through senescence.

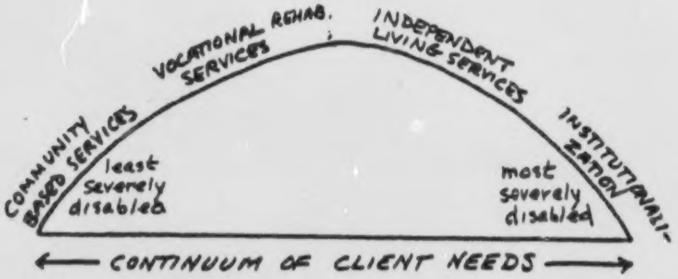
This implies the coordinated development of a capacity to provide five levels of care and service:

PREVENTION → MAINTENANCE → AMELIORATION → HABILITATION → REHABILITATION

In order to insure continuity of services in a holistic framework it is necessary to provide a focal point in government to coordinate both the activities of service providers and the programs under which services are provided. As the principal Federal agency with responsibility for meeting many of the needs of people over a full range of disabilities and levels of disability for people of all ages, it is logical to place this coordinative responsibility in the Rehabilitation Services Administration. As a point of departure, RSA should be given lead agency responsibility for the development of a national Federal policy on disability.

C. Pending the development of a national policy we can offer a conceptual framework for the building of a comprehensive service delivery network for people with disabilities.

Such a network would necessarily include (1) institutionalization for those who are so profoundly disabled that no alternative living arrangements are feasible, (2) independent living rehabilitation, including transitional living, congregate living, and halfway house accommodations, and a broad range of services to develop in disabled individuals who have no vocational goal the capacity to live independently and normally in their homes and communities, (3) vocational rehabilitation for persons, both severely and less severely disabled, who reasonably can be expected to develop vocational goals, (4) community-based services, to insure that a continuum of services is available for all disabled people who are not in institutions. The level of services and the intensiveness of such services would depend on the needs of the individual. Many disabled people will need some services throughout their lifetime, which may not directly relate to the level of their disability. The following schematic portrays in broad terms the scope of this network:



It would be useful to indicate the range of services under these programs:

Community based services (all disability levels, all ages)

equal employment/affirmative action
architectural barrier removal
tax abatements/financial incentives
local information and referral, outreach
public health-prenatal, postpartum testing, immunization
integrative government/social service agency programs
technical assistance to school systems/appropriate education assurance
transportation
recreation
public safety
public awareness and education

Vocational rehabilitation services (working age population, vocational goals)

counseling and guidance
evaluation of rehabilitation potential
provision of aids and devices
maintenance during rehabilitation
interpreter and reader services
vocational and other training services and materials
transportation related to vocational rehabilitation services
restoration services
extended evaluation
family services
placement and followup
recruitment and training services

Independent living services (severely disabled, no vocational goals)

attendant management, attendant care
mobility and transportation
home management, chore services
medical maintenance and self-care
transitional living arrangements
social skills and problem solving
financial management
recreation
peer counseling
sexual and personal adjustment

Institutions (all ages, most severely disabled)

activities of daily living
educational development
medical care, other life sustaining services
physical exercise
social development

D. Survey of services currently provided.

What services are now being provided, and by whom? The vocational rehabilitation program has provided services through a State agency system for many years. Rehabilitation counselors, employed by the State, secure education, training, work experience, diagnosis, evaluation and restoration services for their clients. Much of this is done through purchase of services from public or private rehabilitation facilities, manufacturers of aids and devices, physiatrists, psychologists, and businesses. Education and training and medical care can be coordinated through other programs, such as CETA, title XX, Medicare/Medicaid.

State developmental disabilities councils attempt to leverage and coordinate a wide range of resources for mentally retarded persons and those with cerebral palsy, epilepsy, and autism, without regard to age or employability.

Comprehensive medical rehabilitation centers provide rehabilitation services, primarily with a medical emphasis, to individuals outside the vocational rehabilitation system. These centers are located chiefly in hospital settings and may be supported through foundations, as publicly supported entities, or as private for profit or not for profit operations.

Institutions for mentally retarded, mentally ill, or profoundly physically handicapped individuals are provided by States, city or county resources, and other public and private for profit and not for profit agencies.

Community services and independent living services generally are not provided in a coordinated way. Larger cities may give attention to the specific needs of the disabled, and States have in a few cases established independent living services through vocational rehabilitation agencies with State funds.

The link between vocational rehabilitation services and employment for those who have been rehabilitated has not been addressed in a major way. Traditionally, vocational rehabilitation agencies have viewed their role as one of preparation of the individual for employment.

E. To create a nationwide network of comprehensive services to disabled individuals, mechanisms and delivery systems and coordination points must be established.

- For community-based services, capacity building will be accomplished through regional, intergovernmental resource centers which will provide technical assistance, guidance on integrative programming, model ordinances, public information materials. These centers will aid communities in their regions in developing community service mechanisms. Monitoring of center activities and accomplishments will be done through the Regional Offices of RSA.

- For independent living rehabilitation, grants will be provided to State vocational rehabilitation agencies, to community-based organizations, to private nonprofit and possibly profit-making organizations, and to consumer organizations and cooperatives. Coordination with vocational rehabilitation agencies will be effect to transfer to the vocational rehabilitation program individuals who develop vocational goals as a result of their independent living rehabilitation. Information and referral mechanisms will be expanded at the State and local levels. Guidance and monitoring will be done by RSA.

- The link between vocational rehabilitation and employment will be forged through a major new cooperative effort with business and industry. Vocational rehabilitation agencies will work on a continuing basis with industry councils in major cities and industrial areas to match jobs and vocational rehabilitation clients, including job modification by employers to accommodate individual needs. Field testing, marketing and distribution of new technology aids and devices will be developed through RSA. Cooperative commercial enterprises comprised of handicapped persons will be supported for the purpose of developing and marketing products and services.

- States will be given an opportunity to develop a gatekeeping capacity to prevent institutionalization of individuals where such placement is inappropriate, to remove individuals from institutional settings, and to insure that for individuals for whom institutionalization is required, the best possible conditions are maintained.

- To insure that the rights of disabled individuals are safeguarded, and that voluntary compliance with laws protecting those rights is fully accomplished, technical assistance to States, government contractors, and recipients of Federal financial assistance will be provided. Protection and advocacy systems will be expanded in each State. Community-based offices will provide counseling to the disabled on their rights under law, and on means to break down barriers that confront them in the environment. A nationwide client assistance program will provide ombudsmen for insuring that vocational rehabilitation clients receive appropriate attention to their needs.

- To eliminate fear, mistrust and misunderstanding in the community so that attitudinal barriers and impediments to community support can be removed, community advocacy and information functions will be established through the regional centers described above. Public forums and discussions will be encouraged.

F. Conclusion.

Many additional challenges face our government and our society in the effort to provide full quality and equality of life for America's disabled people. Among these are full utilization of technology, medical and biomedical advances in disability prevention and restoration; creation of a coordinated, nationwide program of deinstitutionalization; providing the fullest educational opportunity for disabled children through a fully coordinated Head Start - special education - vocational education - vocational rehabilitation program.

It is clear that the legislative proposals we are presenting are modest but affirmative steps toward building a comprehensive service network for our disabled citizens. They are initial steps, but important ones, and they must be adopted if we are to realize our goal of filling the major gaps in services and the mechanisms to deliver them. The momentum for making truly great strides in bringing the disabled into the mainstream of America must not be lost.

VII. Plans for the Future: A Tentative Agenda

As indicated earlier in this paper, the design of a panoply of new approaches to address the comprehensive needs of the disabled in our society must await the development of a national, coordinated policy. Further, with respect to additional major program initiatives for the Rehabilitation Services Administration, the creation of a policy development, analysis, and long range planning capacity will greatly improve our ability to recommend new directions.

Tentatively, however, we are looking toward implementation of new concepts in a number of areas. Three of those have been presented to the Secretary as major legislative initiatives — an independent living rehabilitation program, an accelerated employment and training program, and a community assistance and public awareness program. The authorization levels for these three proposals total $96 million. That modest funding level will not, of course, take care of all the needs. But it will make a difference to thousands of disabled people, and the amount expended will be returned manyfold in terms of cold economic justification. There is no way to place a quantifiable value on improved quality of life, improved self-image, social acceptance, or job satisfaction.

Some additional new directions we will be exploring include:

- Working toward a fully coordinated Head Start - special education - vocational education - vocational rehabilitation program, nationwide.
- Undertaking a comprehensive national survey of disability and service needs, with consequent development of a national data system on disability.
- Mounting a major outreach and referral program with respect to disabled individuals who are most egregiously underserved — those with multiple handicaps of physical or mental disability combined with cultural and economic deprivation.
- Creating a coordinated program of deinstitutionalization involving transitional living, group homes, and habilitation and rehabilitation services.
- Eliminating disincentives to rehabilitation, including the retention of Medicare/Medicaid benefits and food stamps after employment.
- Supporting legal assistance centers for the disabled to protect their rights under title V of the Rehabilitation Act.
- Establishing a nationwide system of client assistance programs so that, through ombudsmen, disabled individuals will be able to "fight the system" to obtain the fullest possible service benefits.

- Demonstrating new approaches to meeting the transportation and residential needs of disabled people.
- Initiating a cooperative research effort in central nervous system (spinal cord) regeneration, and in areas of disability prevention, amelioration, and treatment.
- Adopting a new focus for international rehabilitation interchanges to take advantage of technological and service delivery innovations of developed nations.
- Exploring ways to meet the need for new or renovated rehabilitation facilities and physical improvements in institutions which house physically and mentally disabled people.

These are exciting times for disabled Americans because the potential exists for dramatic breakthroughs in their well-being. We must have the will and the determination to see to it that being disabled in America is not a continuation of that which has gone on before. We must, as a government, reinforce our commitment to meet head-on one of the major challenges of our day — bringing into the mainstream of American society a vulnerable and precious human resource — the millions of disabled citizens in our land.

We now have a panel on the task force report on definition of developmental disability, Mr. Norman V. Lourie, chairman of the task force on definition of developmental disabilities and executive deputy secretary, Pennsylvania Department of Public Health. We welcome you.

Dr. Louis Z. Cooper, who is professor of pediatrics, Columbia University, former vice chairman of the National Advisory Council on Developmental Disabilities who represents the majority report, and Hon. Mary Lou Munts, State representative from Wisconsin, who is a member of the task force on definition of developmental disabilities, representing the minority report, and Dr. Elinor Gollay, project director, ABT study of definition of developmental disabilities.

We welcome each of you here. We appreciate your presence. Your statements will be made part of the record in full. If you can highlight your statement for us, it will be helpful.

STATEMENTS OF NORMAN V. LOURIE, CHAIRMAN, NATIONAL TASK FORCE ON DEVELOPMENTAL DISABILITIES; ELINOR GOLLAY, Ph. D., PROJECT DIRECTOR, STAFF DIRECTOR (DD); LOUIS Z. COOPER, M.D., PROFESSOR OF PEDIATRICS, COLUMBIA, ON BEHALF OF MAJORITY VIEW; HON. MARY LOU MUNTS, WISCONSIN STATE REPRESENTATIVE, ON BEHALF OF MINORITY REPORT

Mr. Lourie. Thank you very much.

We are pleased to be here. We suggest that I open briefly with a summary; then Dr. Gollay, who was staff director, will talk about the processes; Dr. Cooper will describe the majority report and Mary Lou Munts the minority. Then we will be available for questioning.

Mr. Rogers. That will be fine.

Mr. Lourie. You do have a copy of the report and I have provided for today, what amounts ot a brief overall summary [see p. 106].

I would like to say a little about the Task Force and the report. It was a wide open process. The way members of the task force were chosen; access to the documents and the task forces' work on a day-by-day basis were also wide open to hundreds of individuals and organizations who had relevance and interest in the work. A newsletter and other material were distributed.

I would also point out that our single task was, at the request of Congress, to study the definition. In order to study the definition and its relevance, however, we did have to look at what surrounded the definition.

In our meetings we were presented with staff documents and documents from the field which dealt with such issues as the nature of the population group and the criteria that should be applied in order to determine who is included within the term. We studied documents that defined the main issues that derived from the nature of the current definition and program as it is legislatively mandated and as it is operated, particularly at the State level.

We looked at concerns that were derived from the broader context in which the developmental disabilities program operated at the

Federal and State levels. We looked at implications for the various populations that might be excluded or included in the definition, depending on which kind of definition we would come up with.

Finally, while it was not our task to evaluate this program, to look at what it was doing, how well it was doing, and whether or not we thought the program was effective or not effective, it was inevitable that we should have come across some of these questions. We debated some of them but without coming to a conclusion. In the report we stated what seemed to us to be some of the major policy issues.

It is quite clear from your questioning earlier today that these are policy issues and dilemmas that face Congress, the people in the program and the people in the field. We summarized four of them. I would like to repeat them before we go on.

One is that there is a lack of clear responsibility at the State and apparently at the local level for care of the developmentally disabled population and for all the severely handicapped, no matter how defined, and a lack of direct link between the State service program and a Federal service agency for the total developmental disabled population, and for its largest group, the mentally retarded.

Second, there is a lack of clear responsibility at the individual client level for coordination and case management of the many services which developmentally disabled individuals require as well as all of the handicapped.

Third, there is a lack of coordination between the major missions of the developmental disabilities program and its actual authority, both at the national and State levels.

Finally, there is a general lack of clarity concerning the purpose of the developmental disabilities program. People vary in their opinions as to what it is supposed to accomplish.

With that, I will ask Dr. Gollay to describe the process of how we got the report and recommendation before you.

Mr. ROGERS. Thank you very much, Mr. Lourie.

[Testimony resumes on p. 129.]

[Mr. Lourie's prepared statement and attachment follow:]

TESTIMONY BY:
NORMAN V. LOURIE
CHAIRMAN
NATIONAL TASK FORCE
ON DEVELOPMENTAL DISABILITIES
FOR

SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT
OF THE COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE
HOUSE COMMITTEE
U. S. HOUSE OF REPRESENTATIVES
WASHINGTON, D. C.
APRIL 4, 1978

NORMAN V. LOURIE
EXECUTIVE DEPUTY SECRETARY FOR
FEDERAL POLICY AND PROGRAM
PENNSYLVANIA DEPARTMENT OF PUBLIC WELFARE

INTRODUCTION

I very much appreciate the invitation to report to your Committee the recommendations of the National Task Force on the Definition of Developmental Disabilities. This Task Force carried out the Congressional mandate to the Department of Health, Education and Welfare for a special study on the Definition of Developmental Disabilities.

The Task Force represented a wide range of experts and interests. A copy of the report was transmitted to the Committee, on November 3rd, and we hope that the Committee will see fit to include the report in its record. Following the Act of Congress, in Section 301(b) of Public Law 93-104, the Developmental Disabilities Office, of the Department of Health, Education and Welfare awarded a contract to Abt Associates, Inc., to conduct the "Independent Study of the Definition of Developmental Disabilities". A National Task Force was established, under my Chiarmanship. The entire Task Force, as well as many individuals and organizations throughout the country, worked hard to contribute to the report. The list of its members is attached.

The Developmental Disabilities Office now in the Human Development Services Administration, of HEW, was most cooperative in this effort. Large numbers of individuals

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AND ORGANIZATIONS RESPONDED TO LETTERS AND DOCUMENTS. RESPONSES WERE THOUGHTFUL AND USEFUL.

THE TASK FORCE WAS CHOSEN THROUGH A CAREFUL PROCESS AFTER SOLICITING NOMINATIONS FROM OVER TWO HUNDRED ORGANIZATIONS, AS WELL AS FROM FEDERAL AND STATE PROGRAM OFFICIALS.

THE TASK FORCE MET FOR THREE EXTENDED WORKING SESSIONS. SUB-GROUPS WORKED BETWEEN SESSIONS. ABT ASSOCIATES PROVIDED COMPETENT AND DEDICATED STAFF WORK. THE PROCESS WAS OPEN, THOUGHT-OUT, OPINIONS AND FEEDBACK CAME FROM OVER 500 PERSONS AND ORGANIZATIONS WHO WERE KEPT INFORMED THROUGH NEWSLETTERS, MINUTES, RESEARCH AND BACKGROUND PAPERS. FOR THE WORKING SESSIONS PAPERS ON THE FOLLOWING TOPICS WERE PREPARED:

1. ISSUES SURROUNDING THE NATURE OF THE TARGET GROUP; DEFINING THE CRITERIA THAT SHOULD BE APPLIED IN ORDER TO DETERMINE WHO IS INCLUDED WITHIN THE RUBRIC "DEVELOPMENTAL DISABILITIES;"
2. DEFINITIONS OF THE MAIN ISSUES THAT DERIVE FROM THE NATURE OF THE CURRENT DEVELOPMENTAL DISABILITIES PROGRAM BOTH AS IT IS LEGISLATIVELY MANDATED AND AS IT IS ACTUALLY OPERATED, PARTICULARLY AT THE STATE LEVEL;
3. CONCERNS DERIVING FROM THE BROADER CONTEXT IN WHICH THE DEVELOPMENTAL DISABILITIES PROGRAM

OPERATES AT THE FEDERAL AND THE STATE LEVELS;
AND

4. IMPLICATIONS FOR POPULATIONS INCLUDED OR EXCLUDED FROM THE DEFINITION.

RECOMMENDED DEFINITION

THE RECOMMENDATION OF THE TASK FORCE FOR THE APPROPRIATE BASIS OF A DEFINITION STATES:

FOR PURPOSES OF THE DEVELOPMENTAL DISABILITIES ACT, A DEVELOPMENTAL DISABILITY IS A SEVERE, CHRONIC DISABILITY OF A PERSON WHICH:

1) IS ATTRIBUTABLE TO A MENTAL OR PHYSICAL IMPAIRMENT OR COMBINATION OF MENTAL AND PHYSICAL IMPAIRMENTS;

2) IS MANIFEST BEFORE AGE 22;

3) IS LIKELY TO CONTINUE INDEFINITELY;

4) RESULTS IN SUBSTANTIAL FUNCTIONAL LIMITATIONS IN THREE OR MORE OF THE FOLLOWING AREAS OF MAJOR LIFE ACTIVITY:

A) SELF-CARE,
B) RECEPTIVE AND EXPRESSIVE LANGUAGE,
C) LEARNING,
D) MOBILITY,
E) SELF-DIRECTION,
F) CAPACITY FOR INDEPENDENT LIVING, OR
G) ECONOMIC SELF-SUFFICIENCY; AND

5) REFLECTS THE NEED FOR A COMBINATION AND SEQUENCE OF SPECIAL INTERDISCIPLINARY, OR GENERIC CARE, TREATMENT, OR OTHER SERVICES WHICH ARE

A) OF LIFELONG OR EXTENDED DURATION, AND

B) INDIVIDUALLY PLANNED AND COORDINATED.

THIS FINAL RECOMMENDATION REFLECTS THE MAJORITY OPINION. EACH ELEMENT OF THE DEFINITION WAS VOTED ON SEPARATELY. IN VIRTUALLY NO INSTANCE WAS THERE A UNANIMITY. SOME DIFFERENCES WERE HELD MORE STRONGLY THAN OTHERS. MOST STRONGLY EXPRESSED WERE THE DIFFERENCES CENTERING AROUND SPECIFICATION OR IMPAIRMENTS AND CATEGORIES OF CONDITIONS.

MINORITY REPORT

THERE IS A MINORITY REPORT WHICH DIFFERS FROM THE MAJORITY REPORT ONLY IN THE RESPECT OF NAMING SOME CATEGORIES IN THE DEFINITION. THE MAJORITY REPORT DEFINES A SEVERE, CHRONIC DISABILITY OF A PERSON WHICH "IS ATTRIBUTABLE TO MENTAL OR PHYSICAL IMPAIRMENT OR COMBINATION OF MENTAL OR PHYSICAL IMPAIRMENTS".

THE MINORITY REPORT PROPOSES THAT THE SEVERE, CHRONIC DISABILITY IS "ATTRIBUTABLE TO MENTAL RETARDATION, CEREBRAL PALSY, EPILEPSY OR AUTISM, OR IS ATTRIBUTABLE TO ANY OTHER CONDITION OF A PERSON SIMILAR TO MENTAL RETARDATION, CEREBRAL PALSY, EPILEPSY, OR AUTISM BECAUSE SUCH CONDITION RESULTS IN

SIMILAR IMPAIRMENT OF GENERAL INTELLECTUAL FUNCTIONING AND ADAPTIVE BEHAVIOR AND REQUIRES TREATMENT AND SERVICES SIMILAR TO THOSE REQUIRED FOR SUCH PERSONS."

LIMITATIONS OF THE MINORITY REPORT

TRANSLATED INTO OPERATIONAL TERMS BOTH PROPOSED DEFINITIONS PROBABLY COULD BE SAID TO COVER THE SAME POPULATIONS. HOWEVER, THE MAJORITY REPORT IS MUCH MORE CLEAR IN THAT IT SPECIFIES ALL OF THE MENTALLY AND PHYSICALLY SEVERELY HANDICAPPED. THE MINORITY REPORT, IN SPECIFYING SEVERAL CATEGORICAL CONDITIONS, DOES NOT DEAL WITH THE OBJECTIONS OF INTEREST GROUPS WHOSE CATEGORIES ARE NOT MENTIONED. AND, PRESUMABLY, THE STUDY WAS DIRECTED BY CONGRESS, IN PART, BECAUSE THESE CATEGORIES WERE UNHAPPY ABOUT NOT BEING MENTIONED. ONE NEEDS TO QUESTION WHETHER THE NON-MENTIONED CATEGORICAL INTERESTS WILL BE SATISFIED WITH THE PHRASE, "SIMILAR TO MENTAL RETARDATION, CEREBRAL PALSY, EPILEPSY OR AUTISM BECAUSE SUCH CONDITION RESULTS IN SIMILAR IMPAIRMENT OF GENERAL INTELLECTUAL FUNCTIONING AND ADAPTIVE BEHAVIOR AND REQUIRES TREATMENT AND SERVICES SIMILAR TO THOSE REQUIRED FOR SUCH PERSONS".

ON THIS GROUND, THE MAJORITY REPORT, WHICH IN EFFECT IS THE RECOMMENDATION OF THE TASK FORCE, IS BROAD ENOUGH TO COVER ALL CATEGORIES OF MENTAL AND PHYSICAL DISABILITY.

DIFFICULTIES IN CATEGORIZING THE SEVERELY HANDICAPPED

IN CONSIDERING THE ISSUE OF CATEGORIES WHICH COULD potentially be listed in a definition--terms applied to conditions that require similar services to mental retardation, cerebral palsy, epilepsy, and autism--the Task Force looked at long lists of terms applied by practitioners to severely handicapped persons. The list included:

Association Deficit Pathology
Blind
Central Nervous System Disorder
Conceptually Handicapped
Congenital Strephosymbolia
Deaf
Diffuse Brain Damage
Dyscalculia
Educationally Handicapped
Hypokinetic Syndrome
Language Disordered Child
Maturation Lag
Minimal Brain Dysfunction (MBD)
Minimal Cerebral Palsy
Multiple Handicapped
Muscular Dystrophy
Neurophrenia
Neurophysiological Dysynchrony
Attention Disorders
Brain Injured
Cerebral Dysfunction
Congenital Alexia
Cystic Fibrosis
Deaf and Blind
Disgraphia
Dyslexia
Hyperkinetic Behavior Syndrome
Language Disability
Learning Disabilities
Minimal Brain Damage
Minimal Cerebral Dysfunction
Minimal Chronic Brain Syndrome
Multi-Sensory Difficulties
Neurological Immaturity
Neurologically Handicapped
Organic Brain Dysfunction

ORGANICITY
PERCEPTUALLY HANDICAPPED
PSYCHOLINGUISTIC DISABILITIES
READING DISABILITY
SPECIFIC LEARNING DIFFICULTIES
STREPHOSYMBOLIA
TOURETTE'S SYNDROME
WORD BLINDNESS
OSTEOGENESIS IMPERFECTION
PRIMARY READING RETARDATION
PSYCHONEUROLOGICAL DISORDERS
[redacted]
SPINA BIFIDA
STRAUSS SYNDROME
[redacted]

THE MAJORITY REPORT, IN EFFECT, SAYS THAT IT WOULD BE IMPRACTICAL AND ADMINISTRATIVELY CONFUSING TO TRY AND SORT OUT A USEFUL AND UNIVERSALLY ACCEPTABLE LIST OF CATEGORICAL TERMS.

DEVELOPMENTAL DISABILITIES POLICY ISSUES

IN PLANNING ANY PROGRAM FOR GROUPS DIFFERENTIATED BY DIAGNOSIS OR CATEGORY ONE IS ALWAYS FACED WITH A TRIANGULAR DILEMMA: PLANNING ON THE BASIS OF FUNCTIONAL CAPACITY ON THE ONE HAND; ON THE BASIS OF CATEGORICAL CONDITIONS ON THE OTHER; AND ON THE THIRD SIDE THE BASIC OPERATIONAL ISSUES OF HOW TO COORDINATE SERVICES IN THE BEST INTEREST OF PERSONS TO BE SERVED.

THE TASK FORCE WAS NOT CHARGED WITH ANY RESPONSIBILITY FOR EVALUATING THE DEVELOPMENTAL DISABILITIES LEGISLATION OR ITS OPERATIONS. HOWEVER, IN DEALING WITH DEFINITIONAL ISSUES IT WAS DIFFICULT TO AVOID CONTACT WITH THE BROAD POLICY ISSUES INVOLVED IN SERVING THE RISK POPULATION UNDER CONSIDERATION.

While not making recommendations on these policy issues, the Task Force addressed four major policy matters and made observations about them:

1. There is a lack of clear responsibility at the state level for care of the developmentally disabled population and lack of a direct link between a state service program and a Federal service agency for the total Developmental Disabilities population and for its largest group, the mentally retarded.

2. There is a lack of clear responsibility at the individual client level for coordination and case management of the many services which developmentally disabled individuals require.

3. There is a lack of correspondence between the major missions of the Developmental Disabilities Program and its actual authority, both at the national and at the state levels.

4. There is a general lack of clarity concerning the purposes of the Developmental Disabilities Program.

1. *There is a lack of clear responsibility at the state level for care of the developmentally disabled population and a lack of a direct link between a state service program and a federal service agency for the DD population and its largest group, the mentally retarded.*

In most states there is no single state operating agency with the clear responsibility for the care of the developmentally disabled population. In some states the Mental Retardation Agency has been retitled a "Developmental Disabilities Agency." In a few of these states the change in title has represented an actual change in the target population for the agency: that is, the agency now serves individuals with epilepsy, cerebral palsy, or autism who are not retarded. However, in virtually all other states the mental retardation agency cannot legally serve this population. Individuals with epilepsy or cerebral palsy, for example, will unfortunately find that many retitled "developmental disabilities" programs in reality are agencies whose primary orientation is still towards mental retardation. Often non-mentally retarded persons are called mentally retarded in order to receive services

In states which have not changed the target population for their mental retardation program, individuals who have cerebral palsy but who are not retarded (for example) are virtually unable to locate any community residence programs comparable to those which are being established for mentally retarded persons. States which have changed their mandates are finding themselves faced with the problem of retraining staff, adding new staff with new skills, difficulties of changing the image and orientation of existing services while establishing new services for a previously unserved and frequently misunderstood population, expanding mandates but not necessarily expanding budgets, etc. As these agencies have expanded their target population to include developmental disabilities other than mental retardation, individuals with other similar disabilities exhibiting the need for similar services (such as spina bifida or muscular dystrophy) increase their demands for access to programs.

The state mental retardation agency comes closest in most states to being the main service provider for a large segment of the developmental disabilities population. It is interesting to note that the state mental retardation agency is the one major state service agency which does not have a direct counterpart at the federal level. There is no single federal agency which is the counterpart to the state mental retardation service system as there are, for example, for the state education, (including special education) department, vocational rehabilitation, public assistance (including SSI), social service, health, mental health and housing programs. Increasingly the federal Title XIX (Social Security Act) program (for expenditure of monies under Medicaid for a wide range of health care including Intermediate Care Facilities for the mentally retarded and other developmentally disabled) is having an extremely strong influence on the shape of state mental retardation programs because many states are putting large amounts of their MR funds into institutions to bring them up to ICF/MR standards, and are therefore having a limiting effect on community programs.

In sum, there are many disabled individuals who cannot now turn to any single state agency as their primary source to provide or secure the total range of services which they need; as the case management link between them and an array of services from multiple agencies. Developmentally disabled persons, as those individuals frequently most in need of multiple services and advocacy, are in a particularly vulnerable position as a result.

2. *There is a lack of clear responsibility at the individual client level for coordination and case management of the many services which developmentallu disabled persons require*

The discussion so far has pointed out some inadequacies at the broad systems level in serving developmentally disabled persons. Task Force members expressed the concern that at the individual client level there tends to be a major case responsibility vacuum. Developmentally disabled persons require services from different agencies and from different disciplines. The lack of a single state agency with responsibility for their care manifests itself at the client level with a widespread lack of adequate case management. While many (federal) entitlements exist for the population (such as 94-142, the Education of All Handicapped Children Act, and Supplemental Security Income), individuals who have multiple needs on a long-term basis are likely to fall through the cracks. At the individual level some type of "placement" agency or case management structure is needed. This agency, in order to be effective, must have the capacity and authority to access services for the DD population. Some experiments in Pennsylvania and Wisconsin should be watched closely. The DD Program, through the DD Council's grants, could be used to fund model service integration projects on behalf of the developmentally disabled population. But this does not in the long run substitute for an operating level entitlement system. While the developmentally disabled population is far from being the only population requiring such service integration, the DD population need for multiple services tends to be greater than for most populations and the ability to access these multiple services tends to be less.

3. *There is a lack of correspondence between the major missions of the Developmental Disabilities Program under the present Act and its actual authority, both at the national and state levels.*

Currently the intended focus of the DD Program (as articulated for example in the statement by Marjorie Kirkland, which appears at the end of Section 4.3) is planning and advocacy at the systems and individual levels.

Interest groups have maintained that only if the DD Councils have approval power over federal program expenditure and state planning will the DD Councils be effective in their systems advocacy and planning roles. However, existing agencies point out that it is not reasonable to expect a council of individuals serving in an advisory capacity outside of the State operating systems, to provide an adequate and effective review of a complex state plan such as that which is required in special education. This situation becomes even clearer when the target population of the DD Program is relatively narrowly defined and not necessarily seen as describing a population which warrants DD Council veto power over state plans intended for much larger groups of individuals.

It seems unrealistic and perhaps inappropriate to expect that the DD Councils as currently constructed will obtain approval power over all state plans for operating agencies affecting the developmentally disabled population. On the other hand, if the program is to be effective as a systems advocacy force, better mechanisms than currently exist will have to be developed and implemented.

In addition, at the individual level, the newly established Protection and Advocacy Systems could provide greatly enhanced access to services. If the Protection and Advocacy programs are truly effective, they will begin to accumulate a history of cases, the documentation of which could serve as a powerful tool for the systems advocacy undertaken by the DD Councils. However, the Protection and Advocacy system is currently inadequately funded and will need a few years of operations before its true potential can be realized. In addition, because it could be seen as threatening to existing generic agencies, special care will need to be taken to ensure that its role is maintained and enhanced rather than dampened. Another major factor is that inherent in most Federal program mandates and in the charge to state operating agencies, there do exist other advocacy functions including those carried by public service and legal services corporations funded by Federal, state and local tax funds and by private funds.

4. *There is a general lack of clarity concerning the purposes of the Developmental Disabilities Program.*

A recurring theme throughout the conduct of the Special Study, both from Task Force members and other interested individuals, was the lack of clarity which exists concerning the purposes of the Developmental Disabilities Program as currently structured. A major confusion exists around the issue of service delivery: many persons see the primary mission of the DD Program as being the provision of services to the target population. For these persons, the small amount of money currently in the DD Program is being spread thin enough now and the potential addition of other groups would endanger those individuals currently covered. The belief that the DD Program is a major service program for the population is reinforced by the situation described above: despite the proliferation of funding sources at the federal level and of operating agencies at the state level, there generally is no single state agency responsible for delivery of services to the disabled population.

Other persons see the DD Program primarily as a planning and advocacy system. They see its primary mission as mobilizing the resources which exist in other state agencies towards meeting the needs of the target population. As an advocacy force within the state, the program could expand its target population without seriously jeopardizing its effectiveness. Indeed, it could be argued that with a larger constituency it could be more rather than less effective. Proponents of this position point out how small the total amount of money is within the DD Program, but how effective that money can be when used to leverage additional sources and to demonstrate the effectiveness of model programs which generic agencies are reluctant at first to try.

The DD Program, regardless of whether it is a service program or an advocacy and planning program, is not clearly understood. As a result, inappropriate expectations are widespread, with the resultant widespread dissatisfaction of unmet expectations. Many disabled individuals and groups of individuals, as evidenced by their strong desire to be included as "developmental disabilities," see the DD Program as an important one for meeting their needs. Indeed, the program has been important in furthering the care of the individuals included both directly through the funding of specific programs and indirectly through increased visibility. Unfortunately, the precise benefits to be derived by inclusion are not clearly understood by many individuals.

In sum, an effort needs to be made to clarify the purpose of the DD Program. As this effort is made, careful consideration should be made of the various purposes which it could or should fulfill for a group of disabled individuals, and consideration should then perhaps be given to a new focus for the program. At the current time it is not adequately funded or structured to be a true service delivery program, yet it has not been successful at convincing people that it is primarily a planning and advocacy program primarily because all other programs have no legal instruction that the DD program is their coordinator.

A statement reflecting the official policy of the program, made to the Task Force by Marjorie Kirkland, Deputy Director of the DDO, is attached at the end of this chapter.

4.3 Implications of the Proposed Definition of Developmental Disabilities for Individuals with Other Disabilities

Part (B) of the section of the Developmental Disabilities Act which mandated the conduct of the study of the definition of developmental disabilities calls for an examination of "the nature and adequacy of the services provided under other federal programs for persons with disabilities not included in. . .[the recommended] definition."

Although it was not possible within the scope of the study to conduct an in-depth analysis of the services, a number of specific efforts were made to obtain information about the nature and scope of current federal efforts to serve persons with all types of disabilities. Until the final recommendation was made by the Task Force it was not possible to identify who was to be excluded from the proposed definition. The excluded population is discussed in Section 2.4 above. Some of the implications of changes in the definition of developmental disabilities as perceived by federal agencies for their programs are described briefly in Section 5.10 below. Key federal programs serving disabled persons are analyzed in Section 5.2 which identifies who is covered.

Although no in-depth study was feasible, an effort was made within the Special Study to determine the extent to which disabled individuals not included in a potential definition of developmental disabilities are eligible for services similar to those which are provided through the Developmental Disabilities Program. It seemed most logical to focus on those specific benefits which disabled individuals are likely to receive through the DD Program:

1. *Comprehensive state planning which identifies the service needs of disabled individuals across all state agencies.*
2. *Review of state plans for use of federal monies to determine their utility to the developmentally disabled population.*
3. *Establishment of specialized protection and advocacy services within each state for the developmentally disabled population.*
4. *The development of individualized habilitation plans intended to identify the total range of an individual's needs across agencies and, potentially, throughout life.*
5. *Flexible monies for filling gaps and demonstrating innovative programs at the state and federal levels.*
6. *State councils with mandated consumer representation which are intended to be the main mechanism for ensuring that the above purposes are carried out at the state level.*

Virtually all these program elements are available in one form or another through other federal programs which serve non-developmentally disabled handicapped individuals. However, there are some unique aspects of the Developmental Disabilities Program which are not available through any other program. These unique aspects include:

1. *A focus on a specific population with an emphasis on an examination of the total needs both of specific individuals and of the total population. This focus on the total range of needs across agencies and across a specific set of services differentiates the DD Program from most of the other federal programs.*
2. *A focus on a specific population for its entire lifetime, not just for childhood, or for its employable years, or adulthood, as do most other federal programs aimed at serving handicapped individuals.*
3. *A focus on accessing generic services and filling gaps in these services rather than on the establishment of a specialized program providing a large amount of direct services.*

4. *A special mechanism for providing protection and advocacy services.*

There does not now exist a comparable program for the remainder of the handicapped population which can act as the focus at the state level for their interests in the way the Developmental Disabilities Program is intended to function. It is, however, difficult to assess the extent to which the non-developmentally disabled population of persons with disabilities require this type of program. It is precisely because of their unique characteristics that the developmentally disabled persons are seen as being more likely than other disabled individuals to require comprehensive services throughout life; are most likely to be excluded from existing service programs including those intended to serve handicapped persons; and are least likely to be able to advocate on their own behalf to ensure that their needs are met.

BACKGROUND PAPERS

THE REPORT ALSO INCLUDES A SERIES OF BACKGROUND PAPERS PREPARED BY THE STAFF FOR USE BY THE TASK FORCE DURING THE STUDY. ABSTRACTS OF SOME OF THE PAPERS ARE INCLUDED IN THE REPORT. FULL VARIATIONS OF THESE AND OTHER RELATED BACKGROUND MATERIALS ARE AVAILABLE IN VOLUME II OF THE FINAL REPORT. THE TOPICS COVERED ARE:

5.1 HISTORY AND BACKGROUND OF THE DEVELOPMENTALLY DISABLED ASSISTANCE AND BILL OF RIGHTS ACT (PL 94-103);

5.2 ANALYSIS OF FEDERAL LAWS AND COMPILATION OF DEFINITIONS PERTAINING TO THE HANDICAPPED AND THE DISABLED IN FEDERAL STATUES AND REGULATIONS;

5.3 AN OVERVIEW OF THE IMPLEMENTATION OF THE DEVELOPMENTAL DISABILITIES PROGRAM;

5.4 A FRAMEWORK FOR THE BASIS FOR A DEFINITION OF DEVELOPMENTAL DISABILITIES: SOME OPTIONS;

5.5 THE DEMOGRAPHICS OF DEVELOPMENTAL DISABILITIES;

5.6 BRIEF DESCRIPTIONS OF SPECIFIC IMPAIRMENTS;

5.7 AN ANALYSIS OF A FUNCTIONAL APPROACH TO THE DEFINITION OF DEVELOPMENTAL DISABILITIES;

5.8 AGE OF ONSET: SOME ISSUES;

5.9 ALTERNATIVE APPROACHES TO A DEFINITION OF DEVELOPMENTAL DISABILITIES: POTENTIAL IMPACTS ON THE STATE DEVEL-

OPMENTAL DISABILITIES PROGRAM;

5.10 SOME FEDERAL IMPLICATIONS OF CHANGES IN THE DEFINITION OF DEVELOPMENTAL DISABILITIES;

5.11 IMPLICATIONS OF THE DEFINITION OF DEVELOPMENTAL DISABILITIES FOR NON-FEDERAL USERS OUTSIDE THE DEVELOPMENTAL DISABILITIES PROGRAM.

PERSONAL OBSERVATIONS

MY RESPONSIBILITY AS CHAIRMAN OF THE NATIONAL TASK FORCE IS TO REPORT TO YOU ON THE RECOMMENDED DEFINITION. I HAVE DONE SO. I TAKE THIS OPPORTUNITY TO MAKE SOME PERSONAL OBSERVATIONS.

AS THE RESULT OF MANY ACTIONS BY CONGRESS AND THE STATES, WE ARE ON THE THRESHOLD, AND AT LONG LAST, ARE ALREADY ENGAGED IN A MAJOR REVOLUTION IN THE WAYS WE SERVE THE HANDICAPPED AND, PARTICULARLY, THE SEVERELY HANDICAPPED IN THE UNITED STATES. THIS COMMITTEE IS WELL AWARE OF THE NEW MAJOR THRUSTS IN THE SSI, EDUCATION FOR THE HANDICAPPED, AND SOCIAL SERVICES PROGRAMS, AS WELL AS THE CONTINUATION AND SOMETIMES EXPANSION OF SUCH PROGRAMS AS CHILD WELFARE, CRIPPLED CHILDREN, VOCATIONAL REHABILITATION, MATERNAL AND CHILD HEALTH, MEDICAID, INCLUDING EPSDT, COMMUNITY MENTAL HEALTH, DEVELOPMENTAL DISABILITIES, ETC. WE ARE INDEED ON OUR WAY TO CARRYING OUT THE COMMITMENT OF A CIVILIZED NATION TO ITS MOST SUFFERING.

HOWEVER, THE MATTER IS COMPLICATED BY FACTS ALREADY KNOWN TO YOU. AT STATE AND LOCAL LEVELS, AT POINTS WHERE WE MEET AND SERVE THE HANDICAPPED AND THE SEVERELY HANDICAPPED, THERE IS NOTHING RATIONAL ABOUT THE MANNER IN WHICH WE ARE ORGANIZED TO CARRY OUT THE SERVICE NEEDS. RESPONSIBILITY FOR BITS AND PIECES ARE CLEAR. BUT ONE IS UNABLE TO DISCOVER ANY REAL RESPONSIBILITY FOR TOTAL SERVICES RESPONSIBILITY IN ANY ONE CASE. IF ONE LOOKS AT THE RELATIVE RATIONALITY OF A GENERAL HOSPITAL OR AT A VARIETY OF PUBLIC UTILITES--TELEPHONE, WATER, SEWER, ELECTRICITY--AND COMPARES THEM WITH OUR GENERAL HEALTH AND SOCIAL SERVICES ARRANGEMENTS, THE LATTER ARE UNKEMPT AT THE VERY LEAST.

ONCE OUR SOCIETY IS AGREED UPON THE NATURE OF A PROBLEM IT WISHES TO SOLVE, I BELIEVE IT HAS THREE OBLIGATIONS: TO DETERMINE WHO IS AT RISK; TO DETERMINE WHAT ARE THE NEEDS OF THOSE AT RISK; AND FINALLY TO PUT INTO PLACE WHATEVER ARRANGEMENTS ARE NECESSARY TO GUARANTEE THAT THE NEEDS ARE MET.

WE KNOW THAT THERE ARE APPROXIMATELY TWO MILLION SEVERELY HANDICAPPED PERSONS, WHO COULD FIT WITHIN THE DEFINITION OF DEVELOPMENTAL DISABILITIES--NO MATTER HOW IT COMES OUT. WE ARE ALSO QUITE CLEAR ABOUT THEIR NEEDS, BUT THE ARRANGEMENTS FOR SERVICES IN NO WAY CAN BE DESCRIBED AS PROVIDING GUARANTEES THAT NEEDS ARE MET.

As our Task Force and many others have so well pointed out, an instrument at the Governor's Office level for all of the handicapped or for some of the handicapped, under present Federal legislation, can only have an advisory or a prodding function. Such bodies, even when written into law, as in the Developmental Disabilities legislation, have no power because other myriad Federal legislation do not give them power.

One also has to be concerned about how many coordinating bodies and functions are created to improve services. The Developmental Disabilities legislation deals with the severely handicapped. The Developmental Disabilities Council interacts with many service programs in departments of state government which deal with a wide range of the handicapped. Should there also be state councils for the handicapped in general? If these had the same functions at the state level there would then be at least two bodies dealing with operating level agencies on similar grounds, and if one talks to adherents of other programs which cross operating program lines, a veritable cacophony of coordinating mechanisms could easily be the result.

It would perhaps be ideal if each piece of Federal legislation providing money to states for the handicapped and

AND SEVERELY HANDICAPPED WOULD MANDATE PARTICIPATION IN INTEGRATIVE PROGRAMMING AND SERVICES ARRANGEMENTS. AS IT IS NOW, EACH CATEGORICAL PROGRAM IS RESPONSIBLE ONLY WITHIN ITS LIMITS AND NO ONE PROGRAM IS SUFFICIENT ENOUGH TO MEET ALL OF THE NEEDS OF THE HANDICAPPED AND SEVERELY HANDICAPPED PERSONS. IT WOULD PERHAPS BE IDEAL IF, AT THE OPERATING LEVEL, THERE WOULD BE SOMETHING AS RATIONAL AS THE GENERAL HOSPITAL WHICH ACCEPTS CONDITIONS OF ALL DEGREES, FROM INTENSIVE CARE TO AMBULATORY CARE, AND HAS ITS SPECIALTIES OPERATING EFFECTIVELY AROUND A PERSONS NEEDS WITH A CASE MANAGEMENT AND RESPONSIBILITY FACTOR WRITTEN IN.

OBVIOUSLY, NO ONE COMMITTEE OF CONGRESS CAN DO THIS BY ITSELF. THERE ARE CLEARLY SOME MAJOR GAPS IN FEDERAL PROGRAMS FOR SERVICES TO THE SEVERELY HANDICAPPED. WHILE SSI, VOCATIONAL REHABILITATION, SOCIAL SERVICES, MEDICAID, PUBLIC ASSISTANCE, HOUSING PROGRAMS, ETC, ALL OFFER SOME SERVICE BENEFITS, THERE STILL IS NO PROVASIVE FEDERAL PROGRAM WHICH PROVIDES FUNDS FOR SOME OF THE LONG TIME COMMUNITY LIVING NEEDS OF THE SEVERELY HANDICAPPED, FOR INSTANCE. SOME STATES HAVE DEVELOPED PROGRAMS OF THEIR OWN AND IN THE PROCESS OF DEINSTITUTIONALIZATION HAVE INVESTED CONSIDERABLE SUMS IN COMMUNITY LIVING ARRANGEMENTS, RESPITE SERVICES, AND SIMILAR SERVICES WHICH ARE DESIGNED TO KEEP THE SEVERELY HANDICAPPED

LIVING AT THEIR HIGHEST POSSIBLE POTENTIAL IN THE LEAST RESTRICTIVE ENVIRONMENTS. IN SOME INSTANCES THE COUNTIES HAVE BEEN INSTRUMENTAL IN PUSHING THE STATES TO ACCOMPLISH THESE TASKS.

FINALLY, ON ADVOCACY. THOSE WITHOUT POWER NEED SPOKESMEN. ANYBODY OR FORCE WHICH TAKES ACTION IN BEHALF OF A CAUSE IS PRACTICING ADVOCACY. IN MY VIEW, THE HIGHEST EXPRESSION OF ADVOCACY IS NOT ALONE IN THE FLAG RAISING OR FLAG CARRYING. IT IS IN THE ULTIMATE TRANSLATION OF RESULT --THE GUARANTEE THAT THERE ARE SYSTEMS IN PLACE WHICH GUARANTEE THAT NEEDS ARE MET.

THE DILEMMAS ARE COMPLEX AND CLEAR AT THE SAME TIME. I KNOW THAT YOUR COMMITTEE WILL CONTINUE TO GIVE ATTENTION TO THEM. I HOPE VERY MUCH THAT THE NATIONAL TASK FORCE HAS MADE A CONTRIBUTION TO YOUR THINKING AND IT WILL BE USEFUL IN YOUR WORK.

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In addition, the following groups had a representative at each meeting but no consistent member of the Task Force:

American Federation of State, County and Municipal Employees
(AFSCME)/AFL-CIO
Washington, D.C.

Social Security Administration
Baltimore, Maryland

• federal members of the Task Force

STATEMENT OF ELINOR GOLLAY, Ph. D.

Dr. GOLLAY. My thanks also for the opportunity to present our thoughts to you. I will briefly review the history and outcomes of the study. I will not go into detail on the recommendations. I will leave that to the task force members, but I am available for any further questions you might have on the conduct of the project.

I was the project director, staff director, for the task force. The project began at the end of September 1976 and was completed at the end of October 1977. The first major activity was the selection of the membership of the task force and, as Norman indicated, we solicited nominations from over 200 organizations, reviewed existing lists and in general, I think, ended up with a final task force that was broadly representative along many dimensions, geographic, specific disability groups, professional competence.

The task force met normally three times, in February, May, and September. It also met normally with a variety of related organizations, the National Advisory Council on Developmental Disabilities, the National Conference on DD, the Coalition Consumers on DD, and with Federal representatives of relevant agencies.

In addition, there were many other meetings conducted throughout the project. As Norman indicated, materials were sent out and it was in general intended to be a very open process.

The purpose of the project, as we saw it, was to take the DD program as it is currently operating and determine the most appropriate way of describing or defining its target population; that is, who should be included or excluded, given the current DD program. This is primarily a question of policy, a program question, and to some extent a political question.

Second, looking beyond the current structure of the DD program, what grouping of handicapped people makes the most sense in terms of common characteristics and common needs. This was more of a technical question. Both purposes were important throughout the conduct of the project.

The process, as Norm has briefly reviewed it, was that the staff provided the task force with a variety of background terms. The first meeting was intended to identify issues associated with definition.

The second meeting generated alternative definitions which were then circulated widely to obtain reactions. At the third meeting recommendations were made.

The votes at that final meeting were taken on each element of the definition to determine whether or not it was an important aspect of developmental disabilities; if it should be included, in what way should it be included. Those aspects, including two categories of disabilities mentioned, severely or substantially handicapped, age at onset, service needs and chronicity.

Although there was not universal agreement on any one element in the definition, there was general agreement with the major components and only one specific element resulted in a minority report and that was the issue of whether or not specific categories of disability shoud be explicitly mentioned in the definition. You will be hearing about the two recommendations shortly.

In terms of findings and recommendations, I would say that the introductory statement to House bill 11764 quite accurately reflects most of the general concerns and findings of the task force with respect to the general quality of the DD population and its need for visibility. If you will pardon me, the DD population is by definition that group of individuals who are most likely to have many needs and least likely to have them be met.

The task force found that the current definition no longer adequately conveys the concept of developmental disabilities. It is easily misinterpreted, both too broadly and too narrowly. There is not enough emphasis on the pervasiveness and substantiality of the disability, that clarification of the age at onset issue as a very important manifestation is different and important as contrasted with organization during childhood or the developmental years. The task force in general agrees with the concept underlying the current definition.

The desire of the task force—I am speaking in general; obviously there were some disagreements within the group—was not to broaden it to the point of losing its focus or overburdening a relatively small program, but the desire was also to reduce the apparent arbitrary nature of the current grouping by emphasizing common needs and characteristics.

There was a general recognition that the definition question is extremely complex and I would not in any way claim that the study that was conducted examined thoroughly all the issues or repercussions of a definition such as that. Many of the repercussions are not easily anticipated. The data are poor in large measure because the DD population cuts the handicapped population in a different way from the way data are gathered.

It is very hard to come up with accurate estimates, as I think you could tell from the earlier discussion. In many ways a lot of the decisions about specific criteria are as much questions of politics or programmatic orientation as they are a technical issue of who ought to be grouped together.

Very briefly, the task force did try to anticipate what might be some of the major areas of impact of altering the definition. It should be recognized it was at the final meeting that the actual shape of the definition emerged, so it was hard to come up with all of the implications prior to that.

In terms of the impact, first on other Federal programs, there are relatively few that exclusively mentioned DD but the intent was that the DD population retain its visibility and its priority. There are some State agencies that have changed their MRA agency to DD and they would clearly have to cope with any changes.

The intent was not to change dramatically the size and the nature of the target population. The implications, in terms of the DD program itself, of changing the definition have been the most controversial and are extremely difficult to determine.

I would just say, if I could summarize the task force's feeling, that the definition is intended to facilitate identifying and focusing on a specific population and retain the visibility of this population with its extraordinary needs and it not intended then, you know, through the recommendation to result in a merging of this population with the handicapped population at large. It was intended to retain the differences.

Mr. ROGERS. Thank you very much.

Dr. Cooper.

STATEMENT OF LOUIS Z. COOPER, M.D.

Dr. COOPER. Mr. Rogers, thank you very much for allowing me to participate. I am certainly most aware of your long concern and contribution and certainly Dr. Carter's as well. I am most grateful to you for your support, which was most apparent to me during my tenure on the National Advisory Council on Developmental Disabilities.

I was asked to comment on the definition from the point of view of the majority. I will restrict myself as best I can to just that component, although as I heard the previous discussion about who is included and who is excluded and the impact numbers, it was hard to constrain myself from getting involved.

You should know that I speak out of 15 years of experience of listening to and living with my children and adolescents and their families who are the unfortunate victims of a whole host of serious and incapacitating conditions. My posture really is one of a human services professional concerned with all children and all families, but, because of the special experience with the developmentally disabled, I have a particular commitment to seeing that this most needy population is not ignored.

I try to put that commitment in the perspective of the roughly 10,000 abandoned or nomadic children wandering around 42d Street in New York City where I work and the million plus ordinary children in our public schools in New York City who are underserved. But inspite of all that, there still has to be a group whose needs just are of another magnitude than these very needy people.

I have to put some basics on the table. From my perspective as a deliverer of service and listener to families, the DD legislation has helped people. It has helped people whose needs are really hard to comprehend, especially hard to comprehend from the outside. The DD legislation has proven that the Federal Government can play an important role in the process.

I know that you are involved in trying to review the experience of the last decade to see how you can take it the next next steps because we will not solve these problems, but hopeful we can move to some next steps.

The uses of the definition of developmental disabilities have been well established by the literature of the task force and I think it would be wasteful to rehash material which is available in written form to everyone in this room.

I was asked to talk from the position of the majority. What is most remarkable to me is the degree of agreement of 50 committed, hard-bitten, heterogeneous people who got down and argued and hassled for a total of about 9 days over what the definition of developmental disabilities should be.

When we got through, the definitions, both majority and minority, were basically the same. I think that the disagreement in the language is really wiped out from an operational point of view. I am talking from the personal perspective of a ground level provider, working with State and local agencies, and families. The differences in the language are trivial. We are talking about the same people and, therefore, the numbers are no different.

The minority has been concerned about successful administration of the program and felt they had to hang onto some labels in order to make life easier for program administrators and legislators. I think successful administration of the program is important but convenience and ease of administration to me is secondary to getting service to people who need it. I feel as a program administrator that I do not need tight and inadequate labels to know who it is I am supposed to serve. The functional language as expressed in the majority report will provide any legislator and any program administrator with all he needs to know about who is in and who is out.

There certainly is a value to continuity of labels. Nevertheless, that continuity which has really brought us to where we are, through the efforts of people concerned with the mentally retarded, the cerebral palsy, and so forth, can be preserved. I do not think it has to be preserved in the language of the definition.

What about the business of who gets in and who gets out? If a service program looks at the definition with honesty, and no service program has the resources to take care of everybody who comes for help, a service program with integrity can utilize the definition to establish priorities so that those who are most in need are first to receive the appropriate services.

Regardless of the language of the definition, any agency that wishes to skim or cream, to take the easy-to-serve, can keep its numbers up. In fact categories makes it easier because there are plenty of people with epilepsy, cerebral palsy, or some degree of mental retardation who do not need the broad range of services that the substantially handicapped, as defined by functional disability need.

It is most attractive to a program administrator, especially one concerned with turnstiles and numbers, to do just that. Retaining labels in my judgment does not provide integrity where it does not exist.

Another issue with regard to labels and definitions and who is in and who is out and the numbers—in fact the definition with all the elements included may very well decrease the number of people who are the concern of this particular legislation. When individuals with some degree of cerebral palsy, mental retardation or epilepsy no longer need service, they can opt out.

The DD legislation, since its inception, has really been nothing but a broad set of regularly underfunded goal statements. It would be the wildest fantasy, that I know you do not indulge in, to think that moneys that come from the Federal Government for this program can meet the service needs of this tremendous population. In perspective, one institution that we try to work with, the Willow Brook State School, has an annual operating budget that is about the same as the national budget for the whole developmental disabilities program.

Therefore, if developmental disabilities legislation, is to have impact it has to be the kind of planning and accessing and advocacy program which you, by your language, have attempted to create. I would hope that you continue to create it. It is just as easy to plan and advocate for people with multiple sclerosis, osteogenesis imperfecta, and spina bifida as it is for those with severe mental retardation, cerebral palsy autism, and epilepsy.

I am concerned about an enormous demand for additional moneys caused by a definition which really focuses on the substantially handicapped. I think we have to have such a definition. I cannot, as a provider, say to one family, "You may come into our program," and to another family, "You cannot," because of this really trivial difference in their diagnostic labels.

I think the sooner we get rid of these trivial excluding labels, the better off we are. In terms of being too inclusionary, I never saw anyone stay in a group home who did not want to. We are not going to have people striving for service which is inappropriate for them. This whole thing has been an experiment.

The age of onset issue is a complex one and we struggled with it a great deal. No one would question that a 30-year old who as a result of an automobile accident or a stroke while on birth control pills or with increasingly severe multiple sclerosis may have enormous service needs.

Whether or not we decide legislatively to provide for their service needs at the same time we are providing for service needs of people whose impairment begins during an entirely different period is a question that I think you have to address. We as providers can live with what you come out with if you give us the wherewithal.

I was thinking, as Elinor was talking, about grouping of people. Have you ever tried to take eight people at a committee meeting in New York and move them across town to a restaurant? You have to get three taxis, and see how long it takes to decide who pairs off with whom in which taxis.

Certainly to decide to put a 30-year old stroke victim or a quadriplegic victim of a driving accident in the same service system with someone who is three and who has never learned to talk is complex and difficult. Our task force took the term developmental disability as we understood it, and as we thought our professional colleagues understood it, and as we thought we could teach it to others, and gave it back to you in a way we thought would be inclusory.

In summary, we have a long way to go before we will adequately meet the human service needs of all of our citizens. I think in the process of focusing on these who are so substantially impaired, we are learning some lessons that hopefully we can feed back to you and to other people who provide us with the wherewithal so that we can improve our human service systems all around.

Thank you very much.

Mr. ROGERS. Thank you very much.

Representative Munts.

STATEMENT OF HON. MARY LOU MUNTS

Ms. MUNTS. It is a pleasure to be here, Mr. Chairman.

I speak from quite a different vantage point. I think I was one of the few people on the task force who was a public policymaker who was not a specialist in developmental disabilities. I have carried major responsibility in legislation related to the area. Recently, I chaired a committee on alternate care that examined the whole package on deinstitutionlization in Wisconsin. I am not a full timer in this. So I found myself involved with a group of people that I marveled at.

Dr. Cooper is right. There was complete agreement on values but some disagreement on how you get there and the operational side.

In our case—the minority—more came from the State level where programs grow, and we asked ourselves questions about what would be the result of changes.

I was not just on the task force thinking as a legislator with interest in this area. I consulted with our Governor, with our secretary of health and social services, with our development disabilities council and with the various disabilities groups I was acquainted with in the State to reach some judgment as to the direction in which to go.

I reflected back to them what I was hearing from our first two meetings before I decided to join the friendly minority.

I would say that everyone agreed that there should be some fine tuning of the definition to place greater emphasis on severity and also to emphasize that the program is to be more inclusive in that criteria of similar impairment can be used as a way of grouping people who do not come under the four categories named. We came to the minority view for reasons I will summarize briefly.

It is really unfair and unreasonable to raise expectations about available services unless there is sufficient funding to implement the legislation. This is true repeatedly with federally mandated programs. We are not thinking, however, of congressional dollars alone.

As you are aware, congressional dollars in the developmental disabilities program come largely through other funding, title XIX and title XX. Your funding is a very small fraction. In Wisconsin I would esitmate it as five-tenths of a percent of the amount allocated to developmental disabilities through general purpose revenues and Federal funding.

To expand the existing definition without the guarantee of additional dollars, not only on the Federal level in terms of the kind of accessing and advocacy that you want to build into a planning structure, I think would leave great room for more gaps than we now have.

The existing definition has had real value simply because there are categories and there is visibility. I think identifying the specific categories of disabilities as an umbrella has given a kind of visibility to move toward mandated services where previously none existed.

The addition of autism led to greater awareness about what we can do to help the individual with autism. This is not to say that adding a very small category does not give such a category a boost. I think what we are concerned about is adding very broad categories of which the severely disabled population is a very small fraction of that group and yet people in a sense feel they are in.

You have a broad group then that think of themselves as under developmental disabilities and it is very difficult to narrow the target population to a very small sub-group in need of services.

From my perspective, probably the most serious concern that I continually struggled with was that a major change in the Federal definition would have a very unfortunate impact both on our State's legislative and service framework. We happen to be a State that saw the Federal Developmental Disabilities Act as a real opportunity. We passed the State Developmental Disabilities Act right after the Federal law. We built in everything. It is in our civil rights legislation; it is in our civil commitment laws; it is in anyplace that we could put it.

For example, we had a task force on the physically handicapped that came through a whole series of bills and the Developmental Disabilities Council became interested in those bills with the result that developmental disabilities was added to all the physically handicapped legislation.

There is a lot of integration occurring at the State and local level. as people do work together. I think it is a mistake to think that Congress has to group everything because in a sense both at the State and local levels, where it is appropriate, services do get integrated and there are other forces that cause that to happen.

If you change the definition it would automatically ripple throughout our system. We would have to review our statutes as we did on equal rights. We would have to do a title search on developmental disabilities. We already have to some extent been changing the law as you have been changing it. This would be a change that would leave a great deal of uncertainty and confusion, particularly for the local delivery system because we have mandated services through statewide developmental disabilities boards in Wisconsin.

There is either a separate DD board or a combined board that also provides mental health services, alcoholism and drug dependency services. At the local level, people know what they are supposed to do with their fledging delivery system. There is inadequate funding because of the rapid deinstitutionalization in our State just as in many other states.

We are attempting at the State legislative level to meet this gap. I think any dramatic increases in the target group of developmental disabilities that is not well understood and defined would create a disruption and confusion that would ill-serve a program that has accomplished a great deal.

I submitted some additional testimony and do not want to digress from the subject of the definition except to say in a related way, as I looked at your legislation that I received on Friday, I was quite distressed that in effect you are putting the Developmental Disabilities Council back in the service business.

I think this would be a terrible mistake. Our State has moved out of that. It is a planning arm and that is its real value. It cuts across the lines between Health and Social Services and the Department of

Public Instruction. It is involved in planning at the local level as people review the plan and budget of each of our boards. The Developmental Disabilities Council has access to the planning process before it comes out of the pipeline, before budgets are made up both at the local and State level. That is where they have impact.

To give you an example, in our budget review bill, which we just passed on Friday—we have a biennial budget and our second year is a fine tuning of the first—we gave only 4 percent State funds with a 4 percent county match to all our human service funding.

The Developmental Disabilities Council demonstrated the need for $2.5 million additional dollars. Actually, we increased that to $3 million. I want to compare that amount to the $670,000 you provided our council.

It is important to keep the council working on this multiplier effect rather than placing it in a position where its limited dollars must go for Federal mandate. With direct services, you know, it is easy to start saying at the State level, "The Feds are going to do it for us. But unfortunately you are not providing the kind of dollars that make this realistic."

We would rather see you put the dollars where they count and can be used to increase our State dollars to meet the real problems, rather than establishing a funding formula that makes us do things in fragmented ways. It would be my hope that you would in effect keep the ship steady and improve the program rather than change it in ways that I think States which have gone a distance with your help would be ill-served.

[Ms. Munt's prepared statement follows:]

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Committee on Environmental Protection
MEMBER:
Committee on Judiciary
Committee on Criminal Justice and Public Safety

TESTIMONY

Good morning, Mr. Chairman, and members of the House Subcommittee on Health and the Environment. I am Wisconsin State Representative Mary Lou Munts and a member of the National Task Force on the Definition of the Developmental Disabilities. For many years I have been involved in our state legislature in the drafting and passage of several major pieces of legislation affecting persons with developmental disabilities.

I certainly wish to thank the committee for inviting me to testify represent the views of the members of the Minority Task Force. In my testimony I will be presenting the arguments for our position that the disability categories included in the definition of developmental disabilities remain essentially unchanged in the extension of P.L. 94-103.

I also want to say that in my work on the Task Force I stayed in touch with our Governor, the Secretary of Health and Social Services, and the Council on Developmental Disabilities, who also supported the retention of the existing categorical disabilities named in P.L.94-103 and HR 11746. They also liked increasing the emphasis in the definition on severity of the disability and on serving other persons who meet the criteria of similar impairment requiring services or treatment similar to those required by the disabilities named in the law.

The minority position has been taken for the following reasons:

1. It is unfair and unreasonable to raise expectations about available services unless sufficient funding implements the legislation. If Congressional mandates are not supported by adequate dollars, a real disservice is worked to disability groups who will have to compete for the limited monies available. To expand the existing definition without a guarantee of additional dollars would spread the very limited federal funds among many areas of need, leaving any one area of need inadequately served.

2. The existing definition, as contained in P.L. 94-103 and HR 11746, has resulted in significant benefits for our developmentally disabled population. The identifying of specific categorical disabilities within an umbrella developmental disabilities concept has provided visibility and mandated services, where previously none existed.

   For example, with the addition of "autism" to the definition, an awareness evolved of the needs of autistic individuals that might not have occurred under a completely functional definition.

3. Finally, a major change in the federal definition would have an unfortunate impact on the legislative and service framework of many states. Developmental disabilities has become a term which is now relatively well understood and has been incorporated in Wisconsin statutes, ranging from civil rights to mental commitment. At the local level, Wisconsin has mandated county developmental disabilities boards, which operate separately or in a combined board which also provides mental health, alcoholism and drug abuse services.

   A change in the federal definition would automatically ripple throughout our system, requiring innumerable statutory changes and disrupting a fledgling delivery system at the local level. The inclusion of many new disability groups who think they should be served under a functional definition would create conflict and confusion and put strains on a system which is under-funded because of rapid deinstitutionalization.

We would urge you not to change the definition except for the fine tuning suggested by the Minority Task Force. A dramatic increase in the target group of the developmental disability definition unaccompanied by a corresponding increase in federal and state funding would jeopardize the progress made in our state and many others in the last few years.

Mr. **Rogers**. Thank you very much.

Dr. Carter.

Mr. **Carter**. Thank you, Mr. Chairman.

How many of you voted for the majority recommendation? Dr. Gollay, you were one.

Mr. **Lourie**. She was the staff. I was chairman. They did not have a tie and I did not have to vote. I would have voted with the majority, however.

Mr. **Carter**. You would have voted with the majority?

Dr. **Cooper**. I was with the majority.

Mr. **Carter**. Of course, there is a great difference between the majority definition and that which we have had over the years. The majority definition is quite inclusive as I see it. Certainly, I think that all these different physical disabilities need attention. I hope they receive it.

Did your task force consider the approach which Senator Randolph has proposed—to establish a service program for the severely handicapped with no specific mention of the DD population?

Mr. **Lourie**. We did not look at the services program in an evaluative sense. We did look at the service program for the DD population to see how they were being served because of the implications of definition, who would be in and who would be out. We were very much aware of the fact that this population, no matter how defined, has some service relationship to a great many programs, to the medicaid program, to the educational program, the maternal and child health, crippled children, social security, SSI, social services and so on.

We were aware of the fact that none provides adequate, full coverage service to his population.

Mr. **Carter**. That is what I wanted to learn. Are those people who have developmental disabilities receiving the services which they should? You say they are not. Is that correct?

Mr. **Lourie**. Yes. There are lots of gaps.

Dr. **Cooper**. S. 2600 was not available to our task force, so, we did not consider its provisions.

Dr. **Gollay**. One final comment. The task force did explicitly feel that an age of onset or an age of manifestation cutoff point was an important aspect of the population and that to eliminate an age of onset entirely and include all severely handicapped would open the population up to many other kinds of people with very different kinds of needs.

Mr. **Carter**. I believe you both had an age limit of 22. Is that correct?

What cost implications would the recommended definitions have in both the short-term and long-term?

Dr. **Gollay**. We did not work out specific cost implications. However, we do not estimate that under either recommended definition there would be dramatic changes either in the nature of the needs of the population or in the size of the population that would be of concern for the program.

So, aside from the fact that the population needs more services than it is getting now, the changes would not radically alter——

Mr. Carter. Excuse me. You are including both the mentally handicapped and the physically handicapped in your definition. It seems to me that there would be a tremendously increased number in this case that would require more planning.

Dr. Cooper. Dr. Carter, if you just use that first set of qualifiers, mentally and physically impaired, you are absolutely right. In order to be included for purposes of the Act, which is what our focus was, there is a whole set of qualifiers that go after that. So, that if you are talking about, first, children and adolescents, it really would not increase the number who would be eligible under the provisions of the act.

Mr. Lourie. I would like to comment on the service need question.

Mr. Carter. Yes.

Mr. Lourie. When you are out there running a school system or a health or social services or care program and you say, "I want to do something. I want to give services to those who are severely disabled," the place where and the time when the disability arose is less important than the needs of the people at the time they need the service.

Someone mentioned the fact that a 30-year old who had an accident obviously has to be served differently than a 3-year old, even though they both may need the same kind of care. But when that 3-year old is 30, the physical care problem is going to be the same as a newly-ailing 30 year old person and presumably even though we advocate for the early-on manifestation group, seving them in the same living arrangement would probably be quite logical. It would be uneconomical and illogical always to have two different sets of living arrangements based on when the condition was first manifest.

Mr. Carter. I do not believe that always follows. I have seen some developmentally disabled youngsters I thought would never care for themselves or never talk or never be able to distinguish letters or words who have been taught to do so.

I think it is very, very important that we follow these things up more than we have in our committee. Oversight is a very important part of legislation.

Mr. Lourie. Isn't that one of the functions of this kind of mechanism? as Dr. Cooper and Mary Lou Munts pointed out, the developmental disabilities machinery that was set up in State government, has as part of its responsibility as an advocate is to say to the education system, "Now don't you dare give up on some of these learning disabled children because if you give up they are not going to make it."

Mr. Carter. That is part of it. As an advocate you have to take care of that youngster. The chairman is a lawyer and he would understand that. I think that whatever inheritances those youngsters have should be protected under this program.

How many children with dyslexia fit under the existing definition of developmental disabilities?

Dr. Cooper. Dr. Carter, I do not think anyone knows but my guess is that the number is relatively small, Sir.

Mr. Carter. I disagree with that.

Thank you, Mr. Chairman.

Dr. Cooper. I guess relatively small depends on whether it is your child or somebody else's. Certainly, the figures for dyslexia in the broadest sense, which involve a substantial minority of children in certain school systems, would not be included because they do not have the severity of handicap as described in terms of self-care ability and expressive language.

Mr. Carter. Dyslectic comprise 10 percent of our prison population. By not training these youngsters properly at the right time, or by not teaching them to read, they become stubborn and they drop out of school. The first thing you know they do things such as break the law, and they end up being sentenced and sent to prison.

Dr. Cooper. Dr. Carter, I am not an authority on dyslexia.

Mr. Carter. I wish you were.

Dr. Cooper. Yes, I wish there were more authorities. But I suspect that if the average person who you and I would call dyslectic received appropriate educational services at the appropriate time, then all of those other consequences that you just described might be preventable.

Mr. Carter. I think they are but it is very difficult. Some very prominent people have been dyslectic.

Dr. Cooper. Some of my associates are dyslectic.

Mr. Carter. Our last Vice President is supposed to be dyslectic. Leonardo da Vinci was supposed to have been dyslectic as well as other people.

Thank you, Mr. Chairman.

Mr. Rogers. I think it certainly has been helpful to the committee to have your recommendations.

Mr. Chairman, you must have done a good job. You know, Abraham Lincoln tried to decide a question one time. He had it before his Cabinet. He went around; the Secretary of State asked how they voted. Each said "no, no, no, no." Then, Lincoln said "yes" and he said, "The yes has it."

I do not guess you handled them that way. You have the majority and the minority, both reports.

Mr. Lourie. It was a pleasure to chair a group of people with that kind of devotion.

Mr. Rogers. You have done a fine job. We are grateful to all of you. Let me ask this: As we say, we are thinking mainly about the program. What is the best way to get it to work, definitions and all? I guess what we are really concerned about is helping people who need help to get it. Do you have any particular suggestion on the best way to make this program work?

Mr. Lourie. I suppose that each one of us might have a different view of this. My own view, and I have commented briefly at the end of my written testimony, made some personal observations, my own view, is that these persons we are describing who represent the most severe of the handicapped that we need to serve, kind of suffer in spades against a much larger other population who also face the deficits of both the resources and the arrangements for service.

I do think that under any arrangement at the State level, this group needs special attention. If someone asked me if I would want to give this group special attention as against all other groups, I think I would have to say "no." I want to give special attention to all who suffer and need service but that within it or side-by-side with it I want special attention for this group, like the intensive care we give in the general hospital. They are more expensive to care for; they cannot talk for themselves and so on.

I would like to also say to you that the service programs that serve this group are the same service programs, and you know the history of them, which serve the less severe who also are handicapped. Hopefully whatever is done machinery-wise for this severe group ought to be consistent with what we do machinery-wise for the other groups.

Mr. **Rogers.** Thank you so much.

The committee is grateful to each of you and your information has been most helpful to us. The committee will stand in recess until 2 o'clock this afternoon.

[Whereupon at 12 noon, the committee recessed, to reconvene at 2 p.m., the same day.]

AFTER RECESS

[The committee reconvened at 2 p.m., Hon. Paul G. Rogers, chairman, presiding.]

Mr. **Rogers.** The subcommittee will come to order, please.

We are continuing our hearings on the Developmental Disabilities Act Amendments of 1978.

The next witness will be Dr. Elizabeth Boggs, who is past chairperson for the National Association for Retarded Citizens. We welcome you, Dr. Boggs. We are glad to see you back before the committee.

STATEMENT OF ELIZABETH M. BOGGS, Ph. D., HAMPTON, N.J.

Dr. **Boggs.** It is really a pleasure to be back. I am very appreciative of your invitation to appear. I am appearing as an individual since, as past chairperson of the National Advisory Council on Developmental Disabilities, I have no status to speak for them now.

It is true that I also have ongoing associations with NARC, the National Association for Retarded Citizens. They will have their own spokesman later. I am happy to concur in their testimony.

I am also vice-chairperson of the New Jersey Council on Developmental Disabilities and I was a member of the task force on the definition that you heard from this morning.

I am currently also having very interesting experiences as a member of the technical consultant panel to develop a minimum long-term care data set for the National Center for Health Statistics. Most members of the TCP are more familiar with problems of aging than with people who were disabled prior to age 40. It has been very interesting to discuss with them the concept of long-term care applied to people who were disabled earlier in life. We hope the long-term care statistics will begin to reflect needs of developmentally disabled persons along with the elderly.

Mr. **Rogers.** Thank you. Your statement will be made part of the record in full [see p. 151].

Dr. Boggs. Thank you very much. I will try to highlight it.

There is one other activity I have been engaged in that I would like to allude to quickly because of its relevance. I was asked by the Secretary of Health in Pennsylvania to chair a special planning and evaluation committee for the Elizabethtown Hospital for Children and Youth, which is a State-operated orthopedic hospital for children.

I want to tell you two things.

First, the children are admitted to that hospital only because they have orthopedic problems. Nevertheless, half of the children there are mentally retarded.

Second, when our ad hoc committee examined the statistics on their outpatient clinic, we found that the most common reason for termination of services was that the patient reached age 21.

They reached age 21 and were no longer served because that program is dominated by the Federal crippled children's criteria. It is exactly that kind of abrupt interruption of service that is at the core of the thrust of the DD Act to stay away from age limits and to deal with the lifetime continuum across any arbitrary age limiting boundaries.

I do want to congratulate you on the bill. I think the Act as a whole is excellent. Once again we owe many thanks to this committee.

Going back to 1963, the committee was responsible for the Kennedy legislation relative to the construction of MR facilities; then again in 1969 you, yourself, Mr. Chairman, introduced the successor legislation that created the developmentally disabilities program.

I certainly appreciate the consistency with which you have addressed the problem and the depth with which it has been considered by the committee.

I want to concur with the sentiments of Mrs. Jane Belau, who was in the audience this morning. She is the current chairperson of the National Advisory Council on Developmental Disabilities. In her letter of transmittal to the Speaker of the House, dated December 31, 1977, she said:

> Congress created an excellent concept of planning in a comprehensive manner, of coordination, and of service provisions to persons with developmental disabilities. This concept, first introduced in Public Law 91-517, was reinforced through Public Law 94-103.

I think it is our task and your task to assure the further viability of this concept to adapt it to changing times by building on what has gone before. The text of the bill you introduced gives evidence of a thorough review during which much of the obsolete language has been stricken, some superfluous, some deliberately substantive.

We must be sure that in seeking to remedy any weaknesses in the act we do not inadvertently undercut the present act's sources of strength.

Concurrently with the task of examining the actual text of the bill, our activities here today and tomorrow and yours during markup should serve to clarify intents and strengthen consensus about where we are all going to go from here, not in lock step, but freely within the bounds and parameters appropriate to commonly agreed upon overriding goals.

To me it is important to respect the pluralism of methods by which these goals may be legitimately pursued in different States and in different settings.

I cannot emphasize too strongly we need concurrence on the goals themselves and a clear articulation by Congress as to what is expected of all of us.

I am enthusiastic about what you are doing with UAF. I was on the task force that examined the UAF as a result of a grant from the assistant secretary for planning and evaluation. I have to say that it was discouraging to hear Mr. Humphreys say they were just starting to evalaute UAF because evaluation was begun 3 years ago.

I am enthusiastic about the P and A system.

I would like to focus on several issues impacting on the formula grants. Long-term disability is a persistent problem. It does not go away. There are no easy answers.

In his inaugural address, President Kennedy spoke of being called upon "to bear the burden of a long twilight struggle, year in and year out, 'rejoicing in hope, patient in tribulation.'" That is the lot of the people who are developmentally disabled and those of us who live for them and who live with them.

The 1970 legislation which you introduced and which was eventually passed, reflected the complexity of this problem and laid the basis for States to build infrastructures which would be required in order to replace the single agency approach, which had in the past segregated those with chronic disabilities from the open system with multiple linkages to other societal enterprises.

In this context seven years is a short time, and three very short indeed. In fact, the changes wrought by the 1975 amendments have barely borne visible fruit in this interval. This is not due to any foot dragging, but to the nature of the problem and the nature of the process.

We have 54 constituencies working out there on this problem. Like the sailor, each can lose weigh by too much tacking in response to erratic commands from a distant admiral. For this reason I urge you to review the current amendments as a chance to correct course without changing the basic direction or the expected landfall.

I might point out in this connection that during the past 7 years, we have had no less than three administrations and that during this period, Mr. Lynch, the Director of the program, has had no less than six bosses and Mr. Humphreys is the latest. Each one of them comes to us and says, "Give me time to examine the program."

In the meanwhile, the program is proceeding on its own and I might say with remarkable success, although clearly that success is not equally evident in all parts of the country.

To me, the proposed addition of a set of national priorities representative of real needs with new funding and sufficient flexibility not to stifle State level creativity can add momentum, but to many back therein the State capitols and in the communities where the disabled are served, these changes may be seen as a crosscurrent, destructive of progress to date and of the positioning which has been achieved for the next tack.

Depending on their present posture, some States will be more disadvantaged than others by the mandate contained in section 133(b)(4) of the bill, which has to do with percentages to be spent on the new proposed priorities. It does not necessarily follow that the most atypical State is deviating in the wrong direction. It may be the one that is ahead of the crowd. Perhaps we should honor the ISP, namely, the individual State plan, as much as we honor the IHP, that is, the individual habilitation plan.

Specifically, we should be sure that the new priorities serve to augment [illegible] not to divert resources from the present mission. I agree with those who hold that the comprehensive planning activity should be allowed to continue and that the capacity of the councils to exert leverage on other funding sources must be further enhanced.

I think this is particularly true with respect to the anticipated amendments to the Rehabilitation Act. Even if title II does not survive, it is quite clear that there will be major changes in the mission of State rehabilitation agencies and that they will increasingly move to deal with people who do not have a primarily vocational goal. DD Councils must address these new resources.

Our population is clearly within that context. It is also clear that although the State rehabilitation agencies can and should now bite off some new mission, they cannot bite off the whole DD mission, and they do not want it. I might add the VR State directors have endorsed the extension of the DD Act.

One way to make clear the intent to maintain momentum to reinstate the emphasis on State level planning in the statement of specific purposes in your act. In my written statement, I have suggested how that might be done. I will not go into that here.

I want to address, second, the issue of comprehensiveness and how that is defined. Like yourself, I have lived under several Presidents and they all have come into office saying they want to be President of all the people. Congress does not enact laws that tend to be all things to all people. No President sends up a program, even a big package like energy, that can be all things to all people.

So, programs have to have limits, and we have to have some rationale for setting those limits. In the human services field, those limits are usually expressed by specifying either the type of service or the classes of the people to be benefited. Your committee deals with health legislation. You have brought out a very useful initiative in the National Health Planning and Resources Act and you have had a broad target population. That is something for all the people but it is restricted to the domain of health services, and properly so.

Similarly, however, we may have legislation which is defined primarily by the target population and is not limited by the service system. The DD Act is such an act. It is defined by limiting the target population and allowing the service systems to be inclusive. It is in that sense a comprehensive act.

Now, one thing that became clear to me at the White House conference on handicapped individuals, to which I was a delegate from my State, is that the disabled themselves are as diverse as society itself and that there really are limits to ecumenism when practical problems are to be addressed. Because I believe the DD Act should encompass the full range of needed services, I also believe that the target population must be limited by criteria related to common needs.

Both the majority and the minority report of the task force on definition met this criteria, but the definition of severely handicapped in S. 2600, in my opinion, does not. I think that it is important to recognize that that definition in S. 2600, although it might look at first blush to be similar to the DD definition, relaxes four to five of the criteria which now limit the DD definitions, in addition it removes the limit on age of onset, thus admitting to that population many people with cardiac disorders, emphysema, chronical mental illness, and all the disorders and deficiencies that first appear usually in middle and late life. All these would be added to the target population.

In addition to doing that, the criteria of functional impairment are very much relaxed in S. 2600 with the result that I would say, just on substantiality alone, the S. 2600 definition have double the population compared to the Abt definitions.

Mr. Humphreys finally got around this morning to suggest that maybe the DD population was a fifth of the population defined by S. 2600. Yet there is only twice the authorization, not five times the authorization. If one takes into account the differences in substantiality, as well as age at onset the DD population is a tenth of the population defined in S. 2600.

The Senate's proposed legislation made no apologies for not knowing how many people they were counting. I might add, (and this I address particularly to Dr. Carter with respect to your question this morning, Sir, about the impact of including physical and mental impairments without diagnostic categories) that, as Dr. Cooper suggested, if one imposes the other restriction, called for in the Abt study, particularly those relating to age at onset, we do have a criteria to measure who is left out.

If you assume that adults meet the test of substantiality, if they are so disabled as to qualify for social security, then we do have data on adults who were disabled in childhood and who have qualified for social security. We have data on the diagnoses that contribute to most of that group [see p. 183].

More than half of the people in that population are mentally retarded. Another 6 percent or so suffer from mental disorders other than mental retardation. If you add up the disabilities that are currently named in the DD Act, you come to somewhere between 75 and 80 percent of adult disabled in childhood, using the social security test of disability.

I think that gives you some idea about where we are coming from.

Now, I might add, however, that the notion that has been bandied about that planning for two disabilities can be done as cheaply as for one is fallacious. The last time around, you, wisely, in my opinion, added autism to the list of developmental disabilities. I can tell you as a member of a State planning council I have spent more time grappling with autism in the last few months than with all the other disabilities combined.

So, the notion that it does not take any more to plan for a new group is not quite correct. That is not a reason for suggesting that the group should not be redefined. My own preference is for the so-called functional approach but one that is limited by multiple functional impairments, by substantiality and by the age of onset.

People who are disabled from age 3 are different at age 30 than people who become disabled at age 30. Their life history has something to do with it.

Now, I want to say a word or two about the issue of laying on national priorities versus the question of State self-determination. I think that you should know that those priority areas which you set forth in H.R. 11764 were indeed identified last summer by the national organizations who represent consumers, providers, and State agencies, and this is based on informal messages that the members of CCDD were receiving from the field, from consumers back home.

This identification occurred before the 1978 State plans were submitted by the State councils. Interestingly enough, however, when the gaps in services which were identified by the more formal planning processes used by the State councils were tabulated, the same four areas surged to the top of the list of types of service gaps most frequently cited.

More than half of the States identified each of the four areas as being a high priority in that sense.

There is reason to believe that this ranking of those areas reflects in part the difficulty of putting together a package from the so-called generic funding stream, usually because there is some missing part of the package. For example, it has been hard to get funding for the startup costs for group homes. You may be able to get HUD to guarantee your mortgage money and you may be able to get SSI to pay the operating costs, but you have to have startup cost. If that is not there the other things do not come together. So, it is fairly clear to me that there are missing pieces of money and that some DD gap filling money must go into the services. And there must be enough there so that that can happen. That is not to say that DD should become a major component of the funding stream.

Moreover, it is important to bear in mind that there is considerable diversity among the States which is disguised when we get only national averages. You will get a statement that on the average the States expend 30 percent of DD funds on planning.

I have appended to my written statement a chart which you probably can see, and that shows that one State expends 100 percent on planning; another one 95 percent, but several States expend only 5 percent or at most 10 percent. It is all over the lot.

I am not here to say that one is doing right and the other is doing wrong. On the contrary, what you have to do is to look at that scatter in the context of what else is available in each State. To some States planning money is easy to come by in State government. To others it is not there at all. In some States you can get construction funds from State government to pass on to private agencies. In Massachusetts, that is prohibited by law.

So, there is a need to recognize the pluralism, the honest pluralism, the real diversity among the States. I believe that the laying on of some national goals, which I support in principle and indeed in practice, has to be done in such a way that it meets current needs and supports what is under way when what is under way looks good.

We cannot just mandate and pick up something that you have asked the States to do and which is good and say, "Stop and do something else." That would strongly contradict the whole notion of long-range planning. States are now being asked to engage in a 5-year planning cycle but they have never been able to see more than 2 years ahead.

I know that you are pressed for time, Mr. Chairman, and I will therefore stop this presentation, submit a complete statement for the record.

I thank you very much for sponsoring the legislation, you and Mr. Carter together, and for holding these extended hearings which I think will help very much.

[Testimony resumes p. 184.]

[Dr. Boggs' prepared statement and attachments follow:]

STATEMENT

of

ELIZABETH M. BOGGS, PH.D., FORMER CHAIRPERSON

NATIONAL ADVISORY COUNCIL ON DEVELOPMENTAL DISABILITIES

to the

SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT

on

DEVELOPMENTAL DISABILITIES ACT AMENDMENTS OF 1978

H.R. 11764

Tuesday

April 4, 1978

Mr. Chairman,

I am most appreciative of your invitation to appear today in support of H.R. 11764, to extend and amend the Developmental Disabilities Act. This Act owes many of its virtues to this Committee; over the years since 1963, and especially since 1969, you have exercized a consistently constructive influence on the evolution of this multicomponent program, a program which is in many respects unique among Federal activities in support of those missions which, constitutionally, belong to the respective states. Your action in formulating and introducing H.R. 11764 carries forward this tradition.

I concur with the sentiments of Mrs. Jane Belau, chairman of the National Adivosry Council on Developmental Disabilities, as expressed in her letter of transmittal to the Speaker of the House, dated December 13, 1977:

> "Congress created an excellent concept of planning in a comprehensive manner, of coordination, and of service provisions to persons with developmental disabilities. This concept, first introduced in Public Law 91-517, was reinforced and improved through Public Law 94-103."

Our task, your task, is to assure the further viability of this concept, to adapt it to changing times by building on what has gone before. Your text gives evidence of a thorough review, during which much obsolete language has been stricken, some superfluous, some deliberately substantive. We must be sure that in seeking to remedy any weaknesses, we do not inadvertently undercut the present Act's sources of strength.

Concurrently with the task of examining the actual text of the bill, our activities here today and tomorrow, -- and yours during mark-up -- should serve to clarify intents and strengthen consensus about where we are all going to go from here, not in lock step, but freely within the bounds and parameters appropriate to commonly agreed upon overriding goals. To me it is important to respect the pluralism of methods by which these goals may be legitimately pursued in different states and in different settings.

I am enthusiastic about the progress which has been made within the past two years, progress which is all the more remarkable when one considers that so little fiscal growth has been allowed. Your bill reflects a confidence we share in the new Protection and Advocacy Systems; your bill reflects a thoughtful process which has been applied to an overdue remodeling of the statutory base for the university affiliated programs; your bill places the special projects authority more clearly in support of the other three programs, which are themselves more clearly complementary. I have chosen, however, to devote my time today to several issues pertaining to the state formula grant program, because the satisfactory resolution of these issues is critical.

Issue #1

Continuity in Pursuit of Long Term Goals: The Need for Constancy in Mission.

Long term disability (and what is longer term than a disability which begins with life itself) is a tedious problem. It won't go away; there are no easy answers. Its victims, and we who work on their behalf and share their lives, are called, in President Kennedy's words, "to bear the burden of a long twilight struggle, year in year out, 'rejoicing in hope, patient in tribulation...'" The 1970 legislation reflected the complexity of our problem and laid the basis for states to build the intricate structures which would be required in order to replace the isolated single agency systems which have segregated those with chronic disabilities in the past, with open systems with multiple linkages to other societal enterprises. This was not a trivial undertaking.

In this context seven years is a short time, and three very short indeed. In fact, the changes wrought by the 1975 amendments have barely borne visible fruit in this interval. This is not due to any foot dragging, but to the nature of the problem and the nature of the process. The states have now entered on a rolling five year planning cycle, yet, in effect, they have never had more than two years of visibility ahead. Like the sailor, we can lose weigh by too much tacking in response to erratic commands from a distant admiral. For this reason I urge you to view the current amendments as a chance to correct course without changing basic direction or the expected landfall.

To me, the addition of a set of national priorities representative of real needs, with new funding, and sufficient flexibility not to stifle state level creativity (or prevent unconstrained needs assessments) can add momentum, but to many back there in the state capitals, and in the communities where the disabled are served, these changes may be seen as a cross current, destructive of progress to date, and of the positioning which has been achieved for the next tack.

Depending on their present posture, some states will be more disadvantaged than others by the mandates contained in Section 133(b)(4) of the bill. It does not necessarily follow that the most atypical state is deviating in the wrong direction. It may be ahead of the crowd. Perhaps we should honor the Individual State Plan (ISP) as much as we honor the Individual Habilitation Plan (IHP).

Specifically, we should be sure that the new priorities serve to augment, not to divert resources from the present mission. I agree with those who hold that the comprehensive planning activity should be allowed to continue; the capacity of the councils to exert leverage on other funding sources must be further enhanced, particularly vis-a-vis the anticipated amendments to the Rehabilitation Act. If this is your intent, as I believe it is, there is need for more explicit assurance to that effect in the bill. As far as possible new mandates should be laid on in an orderly manner and primarily with new money.

One way to make clear the intent, is to reinstate the emphasis on state level planning in the statement of specific purposes in Section 100. The 1970 Act contained language which was left out in the 1975 amendments, I believe inadvertently. The text is "... to assist the several States in developing and implementing a comprehensive and continuing plan for meeting the current and future needs for services to persons with developmental disabilities." I recommend that this language be restored as the lead clause in Section 100(b)(2) with the addition of the phrase "with priority to those persons whose needs cannot be comprehensively covered, etc..."

In my opinion this change would accomplish three things:

1. It would flag Congressional intent to maintain momentum.
2. It would make clear that the overall goal is services for the developmentally disabled with state level comprehensive planning as a vehicle.
3. It would reaffirm that the core group among the developmentally disabled is composed of those whose needs transcend any single traditional service system or discipline, a characteristic which was recognized in the D.D. Definition Task Force by both the majority and the minority.

Issue #2

Comprehensiveness as a Virtue or Vice in Legislation.

I have lived under ten presidents; almost all of them at one time or another expressed an earnest intent to be "President for all the people." However, no agency, no Committee of Congress, and no bill ever sent to the Hill by a President has ever attempted to provide comprehensively for all the people. Every program must have its limits. In the human services field these limits are usually expressed by specifying types of service or by defining the classes of people, usually a bit of both. In order to set out a domain of action which is of manageable size, one adjusts these limits, with funding in mind. If the scope of services is broad (as it must be in the D.D. Act), then the target population must be more narrowly defined, or vice versa.

If there is one thing that became clear to me at the White House Conference on Handicapped Individuals, it is that the disabled are as diverse as society itself, and that there are limits to ecumenism when practical problems are to be addressed. Because I believe that the D.D. Act should encompass all types of service, whether on a first or second priority basis, I also believe that the target population must be limited by criteria relating to common needs. Both the majority and minority reports of the Task Force meet this criterion. The definition of "severely handicapped" in S. 2600 does not.

Issue #3

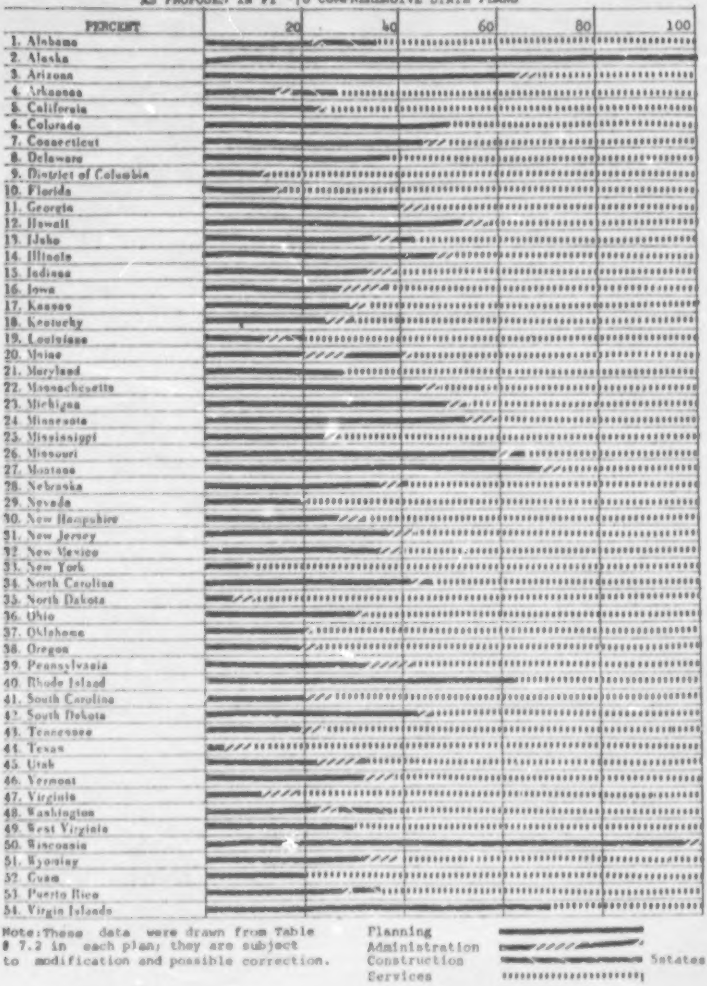
National Priorities vs. State Self Determintion.

The four priority areas which you set forth in H.R. 11764 were identified last summer by the national organizations representing consumers, providers, and state agencies, based on the informal messages they were receiving from the field. This occured before the 1978 state plans were submitted by the state councils.

Interestingly enough, when the gaps in services identified by the more formal planning processes used by the state councils were tabulated, these same four areas surfaced at the top of the list of types of services gaps most frequently cited. More than half the states identified each of the areas. There is reason to believe that this high-ranking reflects in part the difficulty of putting together a package of funding from the so-called generic streams, usually because of some specific missing piece, for example, the start-up costs for a group home.

Nevertheless, to say that more than half of the reporting states already have goals related to community living arrangements or that on the average the states spend 30% of D.D. funds on planning is not to give an accurate picture of the dispersion, the extent of variability. In fact, with respect to the allocations between planning and services, there is wide scatter, as indicated in the attached chart. As you can see, Alaska uses its federal funds entirely for planning, while North Dakota, also a minimum allotment state, uses only 5%. Who is to say that one is right and the other wrong?

CATEGORICAL DISTRIBUTION BY PERCENT OF FORMULA GRANT FUNDS AS PROPOSED IN FY '78 COMPREHENSIVE STATE PLANS



Note: These data were drawn from Table # 7.2 in each plan; they are subject to modification and possible correction.

Issue #4

Planning Versus Services.

Planning and services are not mutually exclusive; on the contrary, to paraphrase slightly: Planning without services is futile; services without planning may be fatal.

Implementation of a plan, i.e. the pursuit of an objective, involves a combination of strategies for producing the end result - e.g. a particular service for developmentally disabled persons. One such strategy is the judicious use of D.D. formula funds to initiate or foster some direct service. Another is to persuade another agency to undertake at least part of the task. Usually a combination of strategies works best. To illustrate this point I am attaching a segment from the 1978 New Jersey State Plan covering one of our twelve plan year objectives, the one pertaining to community living arrangements. You will note the synergistic use of D.D. planning funds, service funds, council initiative (i.e. non-funded "influencing") and particularly the expectation that "other" funds will be mobilized in concert with our own.

Right now it is getting harder to pry loose those "other" funds needed to implement some of the states' highest priorities. There are gaps between federal money streams from our point of view. Last Sunday, Secretary Patricia Harris described the President's recently announced urban policy as providing $8.1 billion to fill the gaps in the existing collection of programs totaling over $30

TABLE 6-2

SUMMARY OF SERVICE NETWORK PLAN YEAR OBJECTIVES & ASSOCIATED IMPLEMENTATION ACTIVITIES

PRINCIPAL AGENCY OR AGENCIES	F.Y. '78 PLAN-YEAR OBJECTIVE	IMPLEMENTATION PROJECT/ACTIVITY	DD PLANNING FUNDS	DD SERVICE FUNDS	COUNCIL INITIATIVE	OTHER FUNDS
	PLAN YEAR OBJECTIVES FOR GOAL A--COMMUNITY CENTERED LIVING: A1(a) To facilitate the development of appropriate standards, procedures and agency responsibility for the licensing of community residential facilities, and to consider the need for comprehensive legislation to address such issues.					
Dept. of Human Services and Dept. of Health		A1(a): to continue to monitor and encourage efforts by the Departments of Health, Human Services and others to resolve the problem, and be prepared to take facilitating action in that regard.			X	X
D.D. Council		-to encourage the drafting of legislation, should this be required to resolve the problem.			X	
	A1(b). To review State and local land use and zoning regulations as they relate to group homes.					
	A1(c). To monitor and encourage efforts to develop and implement appropriate building standards for architecturally barrier free construction.					
Dept. of Public Advocate and D.D. Council		A1(b) and A1(c): to encourage and work with ADDPO in their efforts under the Developmental Disabilities Rights Project to review state and local regulations pertaining				

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PRINCIPAL AGENCY OR AGENCIES	F.Y.'78 PLAN-YEAR OBJECTIVE	IMPLEMENTATION PROJECT/ACTIVITY	DD PLANNING FUNDS	DD SERVICE FUNDS	COUNCIL INITIATIVE	OTHER FUNDS
		to group homes and to monitor the development and implementation of barrier free standards.	X		X	X
D.D. Council	A1(d). To produce and implement a media campaign to foster the development of improved public attitudes regarding the capabilities and needs of the developmentally disabled.	A1(d): to complete production of TV radio public service announcements and see that they are aired.	X		X	
Dept. of Human Services	A2(a). To encourage the success of a pilot program of community services for the developmentally disabled under Title XX Services and its development into a permanent program with an expanded base of funding.	A2(a): to monitor and provide assistance to the pilot program and to work with Title XX staff persons to add additional resources in their State Plan for Title XX funding allocations.			X	X
	A3(a). To disseminate information regarding programmatic alternatives and funding sources.					

TABLE 6-2

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PRINCIPAL AGENCY OR AGENCIES	F.Y.'78 PLAN-YEAR OBJECTIVE	IMPLEMENTATION PROJECT/ACTIVITY	DD PLANNING FUNDS	DD SERVICE FUNDS	COUNCIL INITIATIVE	OTHER FUNDS
Voluntary Agencies		A3(a): to work with and through voluntary agencies to disseminate such information directly to private agencies and to assist their efforts in locating funding.	X		X	X
	A3(b). To explore the feasibility and desirability of integrating individuals with different but complimentary functioning needs within shared living arrangements.					
D.D. Council		A3(b): to undertake a study which may involve a model situation and/or analysis of integration efforts in other areas.	X		X	X
	A3(c). To continue to work with the Department of Community Affairs to maximize resources for the developmentally disabled under the Housing and Community Development Act of 1974 and other existing programs within the Department.					
Dept. of Community Affairs		A3(c): to continue to monitor and encourage the Rental Assistance Program and related activities of the Department.			X	X
	A4(a). To make D.D. service funds available to provide "start-up" costs for community residential arrangements.					

TABLE 6-2

SUMMARY OF SERVICE NETWORK PLAN YEAR OBJECTIVES & ASSOCIATED IMPLEMENTATION ACTIVITIES

PRINCIPAL AGENCY OR AGENCIES	F.Y. '78 PLAN-YEAR OBJECTIVE	IMPLEMENTATION PROJECT/ACTIVITY	DD PLANN-ING FUNDS	DD SERVICE FUNDS	COUNCIL INITIATIVE	OTHER FUNDS
Div. of Mental Retardation (DD Administering Agency)		A4(a): Support for alternative community residential facilities and care systems (also see Table 6-3).		X		
	A4(b): To explore and encourage the availability of other funds to provide "start-up" costs for community residential arrangements.					
D.D. Council		A4(b): to examine possible funding sources (e.g. Public Works Bill) to determine which sources might be used for this purpose, and to encourage their use towards this end.			X	X

billion. On a much smaller scale, the D.D. Act is designed but not funded to do the same thing in our area of endeavor.

It has become fashionable in D.D. circles in recent years to say that the D.D. Act is, or should be, "primarily" centered on planning, and that we should "maintain" this "original" focus. As the author of the 1969 legislation, you, Mr. Chairman, are keenly aware that the original focus of that Act was on services and facilities, with planning as a means to the orderly development of same. The authorization levels spoke to expectations for substantial funding for direct services. When these did not materialize, we began to tailor our task to fit our resources. The result reminds me of the aphorism of a witty British don, who defined "propaganda" as "that branch of the art of lying which consists in almost deceiving your friends without quite deceiving your enemies." We and the BDD have almost deceived each other into thinking that what we've got is what we need; otherwise, the efforts of three years without even a cost-of-living increase would be unbearable.

In short, in certain areas (i.e. certain types of services in certain states) we have scraped the bottom of the present barrel for "other" service funds. Service money must be forthcoming either from within the D.D. Act or without. If the Congress is serious about expecting the states to make progress in the "priority areas" specified in the new proposed bill, it should make such mandates conditional on a corresponding increase in funding. It is not enough to hold states harmless with respect to the amounts previously spent for planning.

More than half of the states identified service gaps in each of the priority areas described in the bill. However, these are not the only gaps, and they are not necessarily the ones the states would all choose to fill with D.D. dollars. States experience gaps in different ways. One has a spend-down provision in Medicaid; another does not. One is bumping its Title XX ceiling; another has a little way to go. The eastern and midwestern states are struggling to close down old institutions; Alaska and Puerto Rico have none to depopulate. The mandate for priority areas should accommodate these legitimate differences.

The priority areas have been defined as "services." It would be more in keeping with the spirit of the present Act, as well as the manner in which state planning and implementation is currently carried out, to recognize that the attainment of "community alternatives," "infant development services" and so on, is not measured solely in D.D. service dollars expended. The example introduced earlier from the New Jersey State Plan indicates that D.D. planning funds may be comingled with "other funds" to contribute to the end result. If it is decided to retain some mandatory percentage expenditure from the total allotment on the designated priority areas, I recommend that credit against the percentage include funds spent in planning and "influencing" related to that objective. As indicated earlier, I would prefer that the mandates in these areas apply only to funds in excess of the 1978 allotments. In this connection it will be important to assure inclusion in the appropriations bill for 1979 of the full Administration request for $46 million for the formula grant.

Issue #5

The Special Case for ICMS or PPC or IPC or Follow-along.

The D.D. program is designed to provide continuity, as needed, over the life span for those whose chronic disability begins at birth or early in life, and to elide the arbitrary discontinuities of age-limited programs such as the Title V crippled children's program, the state mandatory education laws, age factors in SSI, in Medicaid and the rest.

Like the rest of us, developmentally disabled persons may need different types of services at different ages but chronological age is much less important than developmental status when selecting components for a habilitation plan. For this reason, I am pleased that you have avoided the pitfall of trying to be age specific with respect to any service which may be needed prescriptively, including the proposed priority services.

Of particular importance in assuring life-span continuity is the function described in your bill as "individual client management services." This element is not to be confused with protection and advocacy focused on the clients rights, although it may be necessary for a client program coordinator to invoke the Protection and Advocacy system from time to time. To describe what many of us have in mind for this ICMS initiative, I am appending some pages from a report which was commissioned on this topic in 1974 by the

New Jersey Council (Attachment 5-A).

The definition of the ICMS must be read carefully in conjunction with Section 100(b)(2)(A) of H.R. 11764, which Section gives "priority to those persons whose needs cannot be comprehensively covered or otherwise met under the Education of All Handicapped Children Act, the Rehabilitation Act of 1973 or other health, education, or welfare programs." Each of the clients so described is in the center of our target population, and each is the client of more than one agency.

There are some persons who hope and expect that under the P.L. 94-142, all things will flow to all handicapped children of school age, and that the schools can be the primary coordinators for all services, including their health and welfare. I respectfully point out, that even the Task Force which carried out the study on the *The Futures of Children* (Hobbs, 1975) on whose philosophy much of P.L. 94-142 was built, were not so sanguine. They indeed recommended that, for *the majority* of handicapped children, the public school could indeed be the lead agency, in charge of program coordination, tying health and social services as appendages to the Individual Education Plan, but they also recommended that a realistic view be taken of the special concerns for those of "children in need of prolonged assistance" to whom the schools, responsible as they now are for educating each and everyone, cannot alone suffice. Most developmentally disabled children are by definition in need of such multiple services, and should enjoy a truly client-oriented ICMS or "liaison specialist." (Attachment 5-B)

Beginning in 1972 the Rand Corporation undertook an extensive cross agency study of service for Handicapped Youth (age 0-21) for the Office of the Assistant Secretary for Planning and Evaluation, DHEW. One strong conclusion related to the need for what Rand called "Direction Centers." Their initial investigation concentrated on deaf and blind children as prototype handicaps, but their conclusions are valid for all persons with severe persistent disabilities whether children or adults (Attachment 5-C). Your attention is called particularly to the need to keep these direction centers free standing and to prevent clients' being "captured" by one component of the service system.

In my opinion this provision will require a considerable rewrite of the present guidelines issued by the Bureau of Developmental Disabilities in order to emphasize the need for an individual program coordinator (responsible to the client) who is external to any one of the agencies whose services are being coordinated.

This concept may make some service providers a bit uneasy at the start because it is the service delivery counterpart of "deinsitutionalization." In case anyone counters that this is too "idealistic" I point to the fact that in several states machinery is already in place which can carry out this mission with little or no modification and additionally that many small models abound, as Rand has documented. I have attached a news item from California which points up the fact that a trained parent can perform this function, for a handicapped son or daughter, a function which most parents perform for their normal children without training (Attachment 5-D).

Many people now realize that there may be an inherent conflict when an agency which manages or coordinates programs also tries to be a case manager for individuals. Some research-based light is shed on this issue by a study carried out at the University of Wisconsin by Aiken, Dewar, DiTomaso, Hage, and Zeits (Coordinating Human Services, Jossey-Bass, 1975). They studied five demonstration projects on coordinating community services for the mentally retarded. The projects had all been funded under the Rehabilitation Act in the mid-sixties. This study gives added backing to the theses, 1) that Councils have an important systems advocacy and resource-coordination function on the one hand, 2) that multiproblem long-term clients need individual case coordinators on the other, and 3) neither should be subservient to any one component of the service provider hierarchy.

Issue #6

The Concept of "Target Group" vs. "Eligibility"

By their nature some pieces of federal legislation require individually identifiable beneficiaries. The supplemental security income program is a case in point. One is either eligible or not eligible. The D.D. Act is not such legislation. Much of the debate and dissension surrounding the definition of developmental disabilities seems to me to pivot on a misunderstanding on this point. The people who meet whatever definition is used are members of a target group - i.e. a group of people on whom we wish to concentrate some resources in a highly beneficial way, not necessarily in an exclusive way. In fact, the more we move toward integration of developmentally disabled persons into various social groupings which include non-developmentally disabled people, the more we will inevitably permit some of the benefits of D.D. funding to reach others. Indeed, there are times when one should deliberately cast ones bread upon the waters.

Consider the following examples:

Transportation for the transportation dependent: A DD grant, along with other funding, made possible a consolidated transportation system for the elderly and handicapped in a rural area. No one asked for an exact count of developmentally disabled folks getting on the bus.

Early intervention: The program is for infants who are "developmentally delayed." No labels, partly because no diagnoses can be made yet to surely differentiate the aphasic from the mentally retarded child yet both can benefit, as can the autistic child or the dyslexic.

Adoptions: Yes, children with Down's syndrome are adoptable, but the best agency to do it is probably the one that specializes in a variety of hard-to-place children.

Gas liquid chromatography: A number of states have used D.D. funds to make this new equipment available for monitoring anticonvulsant blood levels, in institutions as well as in the community. No one asked whether all the samples were from seizure patients who were severe enough to be considered developmentally disabled, or if they were over 18 years when they had their first seizure. Having such equipment clearly benefited the members of the D.D. target group; that it also benefited others should never be the cause for an audit exception.

I strongly urge the Committee to include report language to the effect that in any activity in which DD dollars primarily support participation by developmentally disabled persons, arbitrary exclusion of persons with other handicaps who need and can use the same services in that particular setting is not required and indeed is to be discouraged.

Attachment 5-A

Précis: LONG-TERM PERSONAL PROGRAM COORDINATION

Summary of a report by Leopold Lippman
for the Developmental Disabilities Council of New Jersey
under a grant to the Mount Carmel Guild of Newark

A personal program coordination service is the integrative mechanism which makes meaningful the continuum of services required to maximize the potential of each developmentally disabled person, and his/her most effective participation in the life of society.

As the Developmental Disabilities Council of New Jersey has said in its draft Comprehensive Plan (1974a), case management is a process of assessment, planning, assignment, follow-up and reassignment, conducted iteratively through the life of the disabled person.[1] The objective is to provide continuity of services from phase to phase in the life of the individual.

The components of a successful personal program coordination service include:

--Service outreach, to find the client in need at the earliest possible stage of his life.

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[1] The Accreditation Council for Facilities for the Mentally Retarded (1973) in its _Standards for Community Agencies_ uses the term "client program coordination" and offers the following definition: "Client program coordination is the process by which responsibility for implementation of the client's individual program plan is established. The client program coordinating process includes providing support, procuring direct services, coordinating services, collecting and disseminating data and information, and monitoring the progress of the client."

--Assessment, evaluation, diagnosis, development of a plan, and counseling of the individual and family.

--Referral to appropriate service resources, and follow-through to insure the rendering of services.

--Follow along; i.e., review, reappraisal and redirection as necessary throughout the life span.

--Record keeping, to facilitate the most effective provision of services, but with safeguards to protect the individual's right to privacy.

--Coordination of the diverse services which the individual may require, including health care, education, vocational training, job placement and oversight, residential services, use of leisure time, financial and legal guidance, and protection from exploitation.

--Standby availability, to help the individual cope with unanticipated problems as they arise.

As the draft Comprehensive Plan notes, it is essential that the services to developmentally disabled persons be conceived of as a lifelong flow, with each phase linked to the past and future according to the needs of the individual.

For the developmentally disabled person, there are special needs for long-term personal program coordination beyond those which exist for other dependent children or adults. The disabled person must not only receive services, but must also receive them in an integrated, sequential manner according to a professionally designed plan which is based upon and responsive to his individual needs. Essential to a successful system of personal program coordination is the establishment of a fixed point of referral, a base to which the disabled person and his family may go, for assistance and counseling whenever required.

Attachment 5- B - Excerpts from:

THE FUTURES OF CHILDREN: CATEGORIES, LABELS, AND THEIR CONSEQUENCES

Report of the Project on Classification
of Exceptional Children

Vanderbilt University
Nashville, Tennessee
September 1974

The goal of ecological planning and programming is to restore the system to productive equilibrium. This is done by providing the critical amount of assistance for the child and for the important people in his environment, so that the system functions on its own in a way that keeps discordance at an optimal level and maximizes opportunities for growth and gratification.

The ecological model belongs to no one discipline. Its use requires someone who can move freely among and communicate with diverse disciplines in the performance of a liaison function--linking up all the individuals concerned about the child and coordinating the planning and programming on his behalf (Williams and others, 1974). The liaison function may be performed by someone from medicine, education, psychology, social work, psychiatry, public health, or other specialty. The critical factor is that he must speak the language of all of these and more. His job begins by defining the ecological system of a particular child who has been identified as in need of assistance. Having visited each of the relevant settings and observed the exchanges between the child and the individuals who are important to him, he must work with all involved to identify the strengths that can be reinforced and relied upon and to pinpoint the sources of discordance. He must obtain from competent authority an evaluation of the child's physical condition, especially noting difficulties that can be corrected. Also, he must be familiar with the resources in his community, so that he knows what forms of help are available. With these sources of information, he must be able to facilitate group problem solving. That is, he must be able to gather together all involved--the child, the parents, the teacher, the grandparents, and any relevant outside resources such as a psychologist, a pediatrician, or a neurologist--and to listen with understanding to each, to guide the planning of a multifaceted strategy for restoring the ecological system to balance. At the end of such a session, each person present should understand clearly how he will contribute to the problem-solving process.

Once the strategies decided upon have begun to be implemented, the liaison specialist must stay in touch with all partners in the effort. He must provide continuing support and must continually assess the effectiveness of the ongoing strategies. As coordinator of a diverse set of activities, he is responsible for monitoring their success or failure, for seeing that successful strategies are phased out and that unsuccessful ones are modified or replaced.

It is possible and we think productive (for purposes of long-range planning as well as for short-term programming) to conceptualize handicapped children as falling into two functionally significant categories in terms of service requirements.

There is a group of children so severely handicapped that they will require lifelong programs of specialized care, therapy, training, and employment opportunities. This group would include the severely retarded, the deaf-blind, the severely crippled, or the neurologically impaired child. Some severely disturbed children also will need lifelong services, but prediction is harder here than for the disorders listed above. The central consideration is the high predictability that these children will need specialized services throughout their lives. Federal, state, and local legislation, insurance plans, health programs, educational programs, employment programs, training programs for professional workers, registers and tracking systems should recognize and provide for these children. The children may be the responsibility of various agencies (including the public schools), but they all have predictable, lifelong service needs. We propose that they be called Children in Need of Prolonged Assistance.[3]

There is a second and much larger group of children who have handicaps (ranging from mild to severe) and who may be expected to benefit from specialized services to the point where they can manage reasonably well in normal settings with occasional assistance or even with no special help at all. This group would include the mildly and moderately retarded, perhaps most disturbed children, the visually impaired and the hard of hearing, the children with specific learning disabilities, and the children with manageable orthopedic and neurological handicaps. We propose that they be called Children in Need of Special Assistance. The agency most involved with them will be the public schools, with specialized assistance being provided by health and mental health services.

> 5.1.1 RECOMMENDATION. In order to reduce fragmentation of services, to give maximum discretion in programming to state and local agencies, and to minimize the effects of labeling on individual children, we recommend replacement of classical categories of exceptionality by two major categories in accordance not with types of disability but with kinds and durations of services needed: Children in Need of Special Assistance and Children in Need of Prolonged Assistance.

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[3] There are similarities here to the group of children embraced by the concept developmentally disabled (see Chapter Three). But the term developmental disability is too restricted, too closely tied to mental retardation services to suffice for the purposes proposed here.

Attachment 5-C

From: Improving Services to Handicapped Children-Summary and Recommendations

Rand Corporation- R-1420/1 HEW May 1974, by Garry D. Brewer and James S. Kakalik.pp17-19

Direction

Ill-coordinated, fragmented, and highly specialized programs tax a parent's ingenuity and perseverance as he searches through the official labyrinth to secure services for his child—an often repeated search, as it proves, because the child's needs change over time. Fully two-thirds of the parents surveyed had problems obtaining service, did not know where to turn for appropriate service, or worse, did not even know what questions to ask. The current service system is decidedly specialty-centered; it urgently needs to become child-centered. Agencies and professionals provide only one or a select few specialized services; and even assuming that each agency and professional performs well, each single service still meets only a fraction of the child's total requirements. Current specialized service professionals should not be blamed for the lack of coordination and direction, for they generally have not been given the specific responsibility and resources to provide the direction service. We need an institution to look at the child as a total human being.

Direction is an information-based service designed for the periodic and systematic matching of a child's needs with the proper mix of services to satisfy those needs as the child ages or improves in response to services and as the system's capacity to serve changes. At least, that is the ideal. Direction is critically important, but is at a primitive stage of development in the United States (see Chapter 3 of Rand Report R-1420-HEW). It is not the main order of business for any of the federal or state agencies serving the handicapped. Even in public welfare agencies, where some direction is given, direction is not a central concern but occurs tangentially as a social caseworker might be required or inclined to assess a client's needs, search out the appropriate services, and then monitor the results. However, welfare is restricted to the poor; besides, most social workers have heavy caseloads, are not rewarded for "direction," and rarely have enough information to direct their young clients, even if they wanted to. The Maternal and Child Health Service also sponsors programs that do limited, noncomprehensive referral. Vocational Rehabilitation programs can provide a comprehensive range of services, but these do not reach young children and must be narrowly aimed at the achievement of a vocational objective. Schoolteachers and nurses sometimes help the parent find needed services, pediatricians sometimes help, and in some states, a "Commission for the Blind" agency provides limited direction service to a segment of the handicapped population.

In short, direction in this country is almost nonexistent, and where it does exist it is sporadic and uneven. And follow up and redirection, implicit in the notion of "periodic and systematic matching," is even less developed. No one really does it, except for a few isolated and dedicated professionals who must make extraordinary and usually costly efforts to understand the overall system well enough to advise in areas outside their specialized competence. Comprehensive information about needed and available services is not generally available, and until it is, direction will remain an unnecessarily limited activity. Thus, the responsibility for matching the needs of the child with available services is a complex and demanding task left almost entirely to the parents, who are generally "ignorant" or poorly informed consumers. There are no generally available and reliable sources of local information to assist them. Without information and a systematic way of matching the child with the set of services he needs, the system often does not work very well. As families proceed from agency to agency, they are liable to be "captured" by one whose services appear adequate or at least better than no service at all. There is no way to find out how much misdirection is represented by capture, but its existence is unquestionable. It is also indisputable that a parent's random and undirected efforts may result in a less than optimal or comprehensive delivery of required services. The deficiency can be dealt with, and the cost of doing so is not prohibitive. In Chapter 3 of R-1420-HEW we discuss a variety of potential solutions, and conclude that one very promising solution is to create Regional Direction Centers for sensorially handicapped children.

Effectively designed Regional Direction Centers would attempt to:

- Develop a one-stop, general information service to match the child's total needs with available services;
- Demand a multidisciplinary effort to balance and integrate the many specialized services needed by the child;
- Emphasize a dynamic, not static, orientation to account for changes in the child's needs over time;
- Maintain comprehensive service information on each handicapped youth;
- Foster client participation;
- Foster the humane personal dimension to create a comprehensive service program specific to each youth's particular needs;
- Serve *all* hearing and vision handicapped youth in the local region by stimulating an active outreach/identification and follow-up program;
- Concentrate on the practicality and feasibility of services and programs by stressing program service evaluation;
- Serve as a local spokesman for hearing and vision handicapped persons generally, and for individual clients particularly;
- Operate independently of the existing service control and incentive systems; and
- Coordinate programs to satisfy existing federal requirements for service integration.

To the extent that the above design characteristics are not implemented, one should expect problems of the following variety: for example, capture of the Regional Direction Center by the existing bureaucracy, overemphasis on certain services, or poor quality direction.

Direction Center personnel could provide outreach, diagnostic, planning, referral, and follow-up services themselves or through consultants as a needed supplement to traditional service providers—e.g., the providers of medical, special education, vocational rehabilitation, and welfare services. This mode of operation would not circumvent or duplicate the present service system, but make it more effective.

Many partial approximations to these design characteristics already exist. We have identified fourteen promising partial models in the United States and eight in Europe. The European direction services we examined are much more developed than those in the United States; but because of severe contextual differences, none of them can be adopted bodily in this country. Besides, we are aware of no model, either foreign or domestic, that is complete enough for such wholesale adoption. Several of the models embody highly promising features, however—in particular, certain aspects of the *conceptual approach* embodied in the proposed New York State "Child Advocacy System," the *technical innovation* represented in Maryland's "Data System for the Handicapped," and several *institutional aspects* of California's Regional Direction Centers for the Mentally Retarded. Judicious selection and combination of the better features of these and other examples would, in our opinion, do much to improve all services to handicapped children.

Attachment 5-D

ARISE for January, 1978–33

In California, a parent can be his own child's 'case manager'

California is the only state with a law that permits a parent to become "program coordinator," or case manager, for his own developmentally disabled child.

Before a parent may take on this role, however, he must first undergo training which includes a 10-week course offered through the community-college system and a year's apprenticeship with a practicing senior counselor, who is his tutor.

The Regional Center of Orange County is the first county to offer such training. Each training wave requires at least 20 parent-participants and, according to Nancy Bradley, the center's manager of client services, there is no shortage of applicants. The center originally planned to start one class in each quarter, but the demand may require that the classes be formed more often.

The first group of parent-managers has completed its community-college training and members are now working under their counselor-tutors. Among the things they are learning are reporting requirements for state and Federally aided programs.

After their graduation, parent-managers will be authorized to convene meetings of professionals and other DD-facility staff to discuss and make recommendations regarding their children's programs. Their authority will be as wide as that granted case managers who are regular staff members.

A good share of the managers-in-training are parents of residents of state hospitals for the mentally retarded. How are hospital officials reacting to the new approach? "Well, we have a lot more public relations to do with the hospitals," said Mrs. Brown. There have been some hairy situations. But Mrs. Brown is confident the new idea will work well once all those concerned have become sensitized to it.

The Regional Center of Orange County has some 3,900 "active" clients on its rolls who are developmentally disabled. "Active" means that the person requires some form of intervention–help–at least once every quarter. It provides diagnoses and evaluations but no other direct services. Instead it links clients with existing services and monitors the results. The center is growing at a rate of about 120 new referrals every month.

CHILDHOOD DISABILITY ALLOWANCES, 1970

TABLE 81.—DIAGNOSTIC GROUP AND PRIMARY DIAGNOSES BY SEX

(PRIMARY DIAGNOSES RELATING TO 50 OR MORE DISABLED CHILDREN SHOWN SEPARATELY)

DIAGNOSTIC GROUP AND PRIMARY DIAGNOSIS	INTERNATIONAL CODE	NUMBER			PERCENT		
		TOTAL	MALE	FEMALE	TOTAL	MALE	FEMALE
TOTAL	---	24,547	12,148	12,399	100.0	100.0	100.0
INFECTIVE AND PARASITIC	000-136	371	180	191	1.5	1.5	1.5
LATE EFFECTS OF ACUTE POLIOMYELITIS	044	298	143	155	1.2	1.2	1.3
OTHER	---	73	37	36	.3	.3	.3
NEOPLASMS	140-239	94	47	47	.4	.4	.4
ENDOCRINE, NUTRITIONAL, AND METABOLIC	240-279	140	59	81	.6	.5	.7
BLOOD AND BLOOD-FORMING ORGANS	280-289	68	34	34	.3	.3	.3
HEREDITARY HEMOLYTIC ANEMIAS	282	51	21	30	.2	.2	.2
OTHER	---	17	13	4	.1	.1	.0
MENTAL DISORDERS	290-315	19,290	9,529	9,761	78.6	78.4	78.7
PSYCHOSIS ASSOCIATED WITH OTHER CEREBRAL CONDITION	293	59	41	18	.2	.3	.1
SCHIZOPHRENIA	295	1,467	866	601	6.0	7.1	4.8
NEUROSES	300	51	21	30	.2	.2	.2
PERSONALITY DISORDERS	301	100	54	46	.4	.4	.4
MENTAL DISORDERS	309	396	209	187	1.6	1.7	1.5
BORDERLINE MENTAL RETARDATION	310	319	154	165	1.3	1.3	1.3
MILD MENTAL RETARDATION	311	1,411	637	774	5.7	5.2	6.2
MODERATE MENTAL RETARDATION	312	2,076	1,023	1,053	8.5	8.4	8.5
SEVERE MENTAL RETARDATION	313	1,076	540	536	4.4	4.4	4.3
PROFOUND MENTAL RETARDATION	314	409	205	204	1.7	1.7	1.6
UNSPECIFIED MENTAL RETARDATION	315	11,803	5,793	6,010	48.1	47.7	48.5
OTHER	---	124	67	57	.5	.6	.5
NERVOUS SYSTEM AND SENSE ORGANS	320-389	3,257	1,655	1,602	13.3	13.6	12.9
LATE EFFECTS OF INTRACRANIAL ABSCESS OR PYOGENIC INFECTION	324	67	35	32	.3	.3	.3
HEREDITARY NEUROMUSCULAR DISORDERS	330	178	130	48	.7	1.1	.4
CEREBRAL SPASTIC INFANTILE PARALYSIS	343	1,313	693	620	5.3	5.7	5.0
OTHER CEREBRAL PARALYSIS	344	70	43	27	.3	.4	.2
EPILEPSY	345	543	246	297	2.2	2.0	2.4
OTHER DISEASES OF BRAIN	347	71	35	36	.3	.3	.3
OTHER DISEASES OF RETINA AND OPTIC NERVE	377	159	62	97	.6	.5	.8
BLINDNESS	379	209	124	85	.9	1.0	.7
DEAF MUTISM	388	135	61	74	.5	.5	.6
OTHER DEAFNESS	389	224	79	145	.9	.7	1.2
OTHER	---	288	147	141	1.2	1.2	1.1
CIRCULATORY SYSTEM	390-458	127	60	67	.5	.5	.5
MUSCULOSKELETAL SYSTEM	710-738	235	81	154	1.0	.7	1.2
RHEUMATOID ARTHRITIS	712	109	29	80	.4	.2	.6
OTHER	---	126	52	74	.5	.4	.6
CONGENITAL ANOMALIES	740-759	590	288	302	2.4	2.4	2.4
SPINA BIFIDA	741	69	27	42	.3	.2	.3
OTHER CONGENITAL ANOMALIES OF NERVOUS SYSTEM	743	63	30	33	.3	.2	.3
CONGENITAL ANOMALIES OF EYE	744	104	55	49	.4	.5	.4
CONGENITAL ANOMALIES OF HEART	746	97	45	52	.4	.4	.4
OTHER CONGENITAL ANOMALIES OF MUSCULOSKELETAL SYSTEM	756	60	39	21	.2	.3	.2
OTHER	---	197	88	109	.8	.7	.9
ACCIDENTS	800-999	249	151	98	1.0	1.2	.8
OTHER	---	126	64	62	.5	.5	.5

From: Social Security Disability Applicant Statistics /1970 ,DHEW No.(ssa) 75-11911

CHILDHOOD DISABILITY ALLOWANCES,*1970

TABLE 82.–LEADING PRIMARY DIAGNOSES BY SEX

PRIMARY DIAGNOSIS	INTER-NATIONAL CODE	NUMBER	PER-CENT	CUMU-LATIVE PER-CENT
	TOTAL			
UNSPECIFIED MENTAL RETARDATION..........	315	11,803	48.1	48.1
MODERATE MENTAL RETARDATION............	312	2,076	8.5	56.6
SCHIZOPHRENIA...........................	295	1,467	6.0	62.6
MILD MENTAL RETARDATION................	311	1,411	5.7	68.3
CEREBRAL SPASTIC INFANTILE PARALYSIS...	343	1,313	5.3	73.6
SEVERE MENTAL RETARDATION..............	313	1,076	4.4	78.0
EPILEPSY................................	345	543	2.2	80.2
PROFOUND MENTAL RETARDATION............	314	409	1.7	81.9
MENTAL DISORDERS.......................	309	395	1.6	83.5
BORDERLINE MENTAL RETARDATION..........	310	319	1.3	84.8
	MALE			
UNSPECIFIED MENTAL RETARDATION..........	315	5,793	47.7	47.7
MODERATE MENTAL RETARDATION............	312	1,023	8.4	56.1
SCHIZOPHRENIA...........................	295	786	6.5	62.6
CEREBRAL SPASTIC INFANTILE PARALYSIS...	343	693	5.7	68.3
MILD MENTAL RETARDATION................	311	637	5.2	73.5
SEVERE MENTAL RETARDATION..............	313	540	4.4	77.9
EPILEPSY................................	345	246	2.0	79.9
MENTAL DISORDERS.......................	309	208	1.7	81.6
PROFOUND MENTAL RETARDATION............	314	205	1.7	83.3
BORDERLINE MENTAL RETARDATION..........	310	154	1.3	84.6
	FEMALE			
UNSPECIFIED MENTAL RETARDATION..........	315	6,010	48.5	48.5
MODERATE MENTAL RETARDATION............	312	1,053	8.5	57.0
MILD MENTAL RETARDATION................	311	774	6.2	63.2
SCHIZOPHRENIA...........................	295	681	5.5	68.7
CEREBRAL SPASTIC INFANTILE PARALYSIS...	343	620	5.0	73.7
SEVERE MENTAL RETARDATION..............	313	536	4.3	78.0
EPILEPSY................................	345	297	2.4	80.4
PROFOUND MENTAL RETARDATION............	314	204	1.6	82.0
MENTAL DISORDERS.......................	309	187	1.5	83.5
BORDERLINE MENTAL RETARDATION..........	310	165	1.3	84.8

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* Refers to persons between 18 and 65 who have been disabled since childhood and who are found eligible because of such disability after retirement, death, or disability of supporting parent.

Mr. ROGERS. Thank you, Dr. Boggs. We appreciate the help you have always given to this committee. We will be in touch with you as we proceed to get additional advice from you.

Now, we do have a large number of witnesses this afternoon. We hope we can hear them all. It would be helpful if you could file your statement and simply give us points that have not been covered or highlight those points in your statement in as brief a period of time as is possible.

The next witness will be a coalition of advocacy groups, Mr. Marion P. Smith who is chairman of the Governmental Affairs Committee, the National Association for Retarded Citizens; Dr. Elsie Helsel who is chairperson of Governmental Activities Committee of the United Cerebral Palsy Associations, Inc.; Ms. Mary Akerley, past president of the National Association for Autistic Children; and Mr. Leo Flannery who is a volunteer for the Epilepsy Foundation of America and is a volunteer from Florida and from West Palm Beach.

I am particularly pleased to have many present from my own area. We welcome all of you to the committee. Your statements will be made part of the record in full. You may proceed. Thank you for being here.

STATEMENTS OF MARION P. SMITH, CHAIRMAN, GOVERNMENTAL AFFAIRS COMMITTEE, NATIONAL ASSOCIATION FOR RETARDED CITIZENS; ELSIE D. HELSEL, Ph. D., CHAIRPERSON, GOVERNMENTAL ACTIVITIES COMMITTEE, UNITED CEREBRAL PALSY ASSOCIATIONS, INC.; MARY S. AKERLEY, PAST PRESIDENT, NATIONAL ASSOCIATION FOR AUTISTIC CHILDREN; LEO FLANNERY, ON BEHALF OF EPILEPSY FOUNDATION OF AMERICA

Mr. SMITH. Thank you, Mr. Chairman.

My name is Marion Smith. I am from Clearwater, Florida.

Mr. ROGERS. Another good Floridian. We welcome you here.

Mr. SMITH. I would like to say to the committee—to be economical of time I will summarize the key points in my prepared testimony. I would like to point out to the committee that my wife and I are parents of a severely retarded child who is residing in an institution for lack of adequate facilities in our community.

I speak to you today representing the National Association for Retarded Citizens. I have had the honor of serving that organization as its national president and for the past 4 years I have served on the State of Florida Developmental Disabilities Council and just recently completed a term on the national council.

I believe you are familiar with NARC. We have 1,900 active units who speak quite loudly to express the needs of those whom we attempt to represent. Our 300,000 members attempt to represent the country's 6 million retarded citizens.

We have been vitally involved with the Developmental Disabilities Act since its inception in 1970. We want to thank you, Mr. Chairman, and the other members of the committee for your support and continued interest.

Let me summarize four key points from my prepared testimony. These will deal with the definition of developmental disabilities, the State plans themselves, the role of the State councils, and the protection and advocacy system.

We, of course, view the DD act as a crucial program for the delivery of services to a portion of our population which is at greatest risk. My first point deals with an issue that you are facing today, the definition of developmental disabilities. As was pointed out, even the task force could not fully agree.

Mr. Chairman, the NARC board of directors has formally endorsed the minority version of ABT task force recommendations for three basic reasons.

First, we feel it retains the foundation of the act and gives continuity and valuable direction to service providers and with reference to the original four conditions, the public and consumers in general have a better understanding of who should qualify for DD services.

Our second reason for favoring the minority report, and I read from my prepared testimony:

> —is that portion the minority version which states that other conditions would be eligible because such conditions result in similar impairment of general intellectual functioning of adaptive behavior and require treatment and services similar to those required for such persons.

The mandate of the act, is quite broad but the resources are totally inadequate to meet the needs of all existing eligible individuals.

We would support the act serving additional severely disabled persons so long as those services are similar to those required by the existing categories. To require the program to begin planning new and different services for a larger group of handicapped individuals would jeopardize the funding base of those now served.

Third, we acknowledge the fact that mentally retarded individuals, simply because they are a larger portion of the population, do constitute about one-half of the DD population. If funding is not increased in a manner commensurate with any projected increase in the scope of the program, our constituents would lose out on existing services.

Let me point out that when the State formula grant program, now currently funded at $30 million, was originally enacted in 1970, it was expected that the formula grant program would be four times that amount in only 3 years.

Obviously, this has not happened. Given these facts, we believe that the target group must be kept the same or only very moderately expanded to severely handicapped individuals who have similar service needs as those now defined in the act.

My second major point: NARC strongly endorses the revisions in H.R. 11764 concerning the State plan provisions. Here, I reflect to you the squeaking wheel I get from our 1,900 local units. As Dr. Boggs pointed out, those four priority areas identified in the plan do indeed reflect from the grassroots, major gap fillers urgently needed: They are (1) individualized client management, (2) infant development, (3) alternative community living arrangements with the necessary quality supporting services, and (4) adult nonvocational social development.

We support the State planning effort which maximizes utilization of Federal resources from the variety of ongoing available resources, such as maternal and child health, crippled children, medical assistance, and other needed State programs.

It is my observation at the National and State level that the DD umbrella is one of the few means to bring together a realistic look as to how all of these resources can meet the needs. DD funds constitute only 1 percent of available funds serving mentally retarded people. The lady from Wisconsin this morning pointed out one-half of 1 percent is the figure in her staff.

My third point is that we have seen controversy, frankly, in some States over the role of the State administering agency and that of the State council. Sometimes we volunteers get noisy but I think that is our job. We see three important roles for the State council: Supervising development of the plan, approval of the State plan prior to submittal to Washington and setting the funding priorities within the State plan.

We observe that these three provisions are covered in section 137 of the bill. We would respectfully suggest that specific explanatory language be included in your House report clearly explaining the State council and State agency roles. This would help avoid some briar patches we have gotten into in the past.

My fourth point: We think that the most exciting new venture in support of persons with developmental disabilities has been the implementation of the protection and advocacy system. We bring to your attention, however, the funding limitations that limit development of these protective mechanisms for these vulnerable people.

The $3 million authorization level in the 1974 act helped get us started. Now, they are in place, they desperately need more funds to operate. More than 40 percent of the States now receive the current minimum allocation, $20,000. One cannot even buy an experienced attorney for $20,000; let alone operate AP and A system.

Therefore, NARC strongly supports the recommended $50,000 minimum allocation.

Those are our key points which we would highlight, Mr. Chairman. We wish to reiterate our continued support for the DD program and for H.R. 11764. We pledge you our support in attempting to expedite its passage.

[Testimony resumes on p. 196.]

[Mr. Smith's prepared statement follows:]

TESTIMONY

on

H.R. 11764

The

DEVELOPMENTAL DISABILITIES ACT

Respectfully Submitted

to

THE SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT

of the

HOUSE INTERSTATE AND FOREIGN COMMERCE COMMITTEE

Presented by

THE NATIONAL ASSOCIATION FOR RETARDED CITIZENS

Witness:

Mr. Marion P. Smith
Chairman
Governmental Affairs Committee
National Association for Retarded Citizens

Tuesday, April 4, 1978

Mr. Chairman

My name is Marion Smith. I speak to you today representing the National Association for Retarded Citizens. I have had the honor of serving this organization as its president and currently serve as the Chairman of the Governmental Affairs Committee. For the past 4 years, I have been a member of the Florida Developmental Disabilities Council and just recently completed a three year term on the National Advisory Council on Developmental Disabilities. As you know, the NARC is the national voluntary organization which represents our country's six million mentally retarded persons. Our organization has been concerned with the Developmental Disabilities program since its inception in 1970, and I wish to take this opportunity to thank you, Mr. Chairman and the other members of this Committee, for your continued support and interest over the years for this vital program.

It is important to state from the outset that NARC views the D.D. Act as a crucial program to the delivery of comprehensive services to that segment of our population that is at greatest risk. As we understand the intent of the Act, the target population to be served is that portion of certain identified disability groups who are the most severely handicapped. For instance, although it is commonly acknowledged that there are six million mentally retarded citizens in the United States, we fully realize that only about one million mentally retarded persons qualify under the D. D. Act. Those one million persons make up the moderate, severe and profound levels of mental retardation.

One of the most important issues facing this Committee and the Congress as you consider the extension of the D.D. Act is the definition of Developmental Disabilities. There has been much debate about expanding the definition and, as you know, the ABT Task Force has completed its independent study and submitted their recommendations. Even the Task Force could not fully agree, although both the majority and minority report recommend appropriate criteria from which to establish eligibility.

After careful consideration, the Board of Directors of the National Association for Retarded Citizens formally endorsed the minority version of the ABT Task Force recommendations. There are three basic reasons for recommending the minority version. First, the minority version retains the foundation from which the Act was originally developed by specifically mentioning mental retardation, cerebral palsy, epilepsy and autism in the definition. This will give the Act continuity and provide valuable direction to service providers, State agencies and others involved in implementing the Act. Without a reference to the original four D.D. conditions, certainly the public and consumers in general will not understand who should qualify for D.D. services if they must use the majority version as the D.D. definition.

Second, and most importantly, is that portion of the minority version which states that other conditions would be eligible "because such conditions result in similar impairment of general intellectual functioning of adaptive behavior and require treatment and services similar to those required for such (mentally retarded, cerebral palsied, epileptic, and autistic) persons." The mandate of the D.D. Act is quite broad, but the resources within the Act are totally inadequate to meet the needs of the existing eligible individuals. NARC fully supports the D.D. Act serving additional severely disabled persons so long as the services required by such persons are similar to those required by the existing D.D. categories. To require the D.D. program to begin planning and establishing new and different services to a new group of handicapped individuals would jeopardize already inadequate services and create impossible to fulfill promises to the newly eligible groups.

Thirdly, we must acknowledge the fact that mentally retarded individuals constitute more than one half of the developmentally disabled population. If the eligibility group is expanded to the extent it would be by adopting the majority report, and if funding for the D.D. program did not rapidly and significantly increase, many mentally retarded persons would lose out on existing services. It is important to realize that the State Formula Grant is currently funded at $30 million. When this Committee originally enacted the D.D. Act in 1970, it expected the formula grant to be funded at $120 million in 1973. It is clear that this Act, as important as it has become for comprehensive State planning and some limited service gap filling, is probably never going to be a major service delivery mechanism. Given these facts, we strongly believe the target group must be kept the same or very moderately expanded to severely handicapped individuals who have similar service needs as the mentally retarded and the other existing developmental disabilities.

NARC strongly endorses the revisions in the State plan provisions contained in H.R. 11764. We are particularly pleased to see D.D. planning and services more sharply focused on four major areas. Individualized client management, infant development, alternative community living arrangements and adult non-vocational social development are indeed the most critically needed services of the developmentally disabled population. The 1900 local units of the Association for Retarded Citizens would certainly agree that these four services constitute a major gap in existing services and need to be expanded immediately to allow mentally retarded persons to continue to lead meaningful lives in their communities. NARC also supports the retention of the planning effort at the State level to maximize the utilization of Federal resources from such services as maternal and child health, crippled children, medical assistance and other Federal/State programs. Since the D.D. funds constitute only about 1% of the expenditures at the State level for mental retardation and D.D. services, it is vital that all other available programs and funds be fully known, understood and utilized. We endorse Section 133(b)(4)(B)(iii) which holds States harmless to protect their previous expenditures for planning purposes. This is an important provision to allow States who have invested substantial sums in planning to continue such activities.

We support the escalating authorization levels through fiscal year 1981 for the State Formula Grant. Increased appropriations in this program will allow us to make a major dent in some of the important service areas. Of major importance is the raising of the minimum allocation for the State Grant program from $150,000 to $250,000. Thirteen States (approximately 25%) are at the minimum allocation. Operating the D.D. program at the current level becomes a major burden. Given the complexity of the planning, and the expensive services, we commend you for increasing the minimum allocation so that the smaller, less populous States are better able to fulfill their responsibilities under the D.D. Act.

NARC endorses the revision in the State Planning Council section (Section 137). We agree with the revised composition of the consumer representation on the State councils and suggest a minor modification to allow one of the representatives of mentally impaired developmentally disabled to be a relative or guardian of an institutionalized person with a developmental disability. This would conform to a similar provision in the composition of the National Advisory Council on Developmental Disabilities (Section 108).

One of the most controversial areas in the past implementation of the Act has been the roles of the State Administering Agency and the State Planning Council in the development of the D.D. State Plan. NARC envisions three important roles for the State Council to assume in the plan development:

1) Supervising the development of the Plan, regardless who actually prepares the Plan
2) Approval of the complete Plan prior to submittal to HEW; and
3) Setting the funding priorities within the State Plan, with subsequent implementation of such priorities by the implementing agency.

We believe these three provisions are adequately covered in Section 137 but suggest that specific explanatory language be included in the House Report clearly explaining the State Council and State Agency roles, especially in the priority setting process.

The most exciting new venture in the D.D. field is the recent implementation of the D.D. Protection and Advocacy Systems throughout the country. This system, when fully implemented, will provide full protection for our developmentally disabled population, which is obviously one, if not the most, vulnerable segment of our society. We commend this Committee for establishing these systems in the 1974 D.D. Amendments. The authorization levels in the 1974 Act were very low ($3 million) on the basis that the systems would be planned and developed during that time. Now that the systems are in place, they desperately need more funds to operate. The NARC strongly supports the increased authorization levels in the P and A system and would urge the Committee to consider a further increase in such authorization levels. In addition, an increase in the P and A minimum allocation is vital. More than 40% of the States now receive the current minimum allocation ($20,000). This sum can't even buy an experienced attorney, let alone operate a P and A system. Our organization is pleased to support your recommended $50,000 minimum allocation. This will greatly aid the P and A systems getting off to a good, solid start.

NARC supports the retention of the provisions concerning the rights of the developmentally disabled, habilitation plans and the employment of handicapped individuals. These sections reflect current trends and practices and will continue to assist the developmentally disabled population to obtain appropriate needed services. NARC also supports the revised sections on purposes and the National Advisory Council on Developmental Disabilities. We are particularly supportive of the new provision mandating the development of a national plan for meeting the identified and unmet needs of developmentally disabled persons. The role of the NACDD in developing such a plan is most appropriate and commendable.

The most disappointing aspect of the implementation of the 1974 D.D. amendments is HEW's failure to meet the timelines to develop a comprehensive evaluation system. We are aware that progress is being made toward the completion of this system. We concur with the revised timetables for full implementation by HEW and the States of this system.

NARC also endorses the various revisions in Part B of the Act, the University Affiliated Programs. The revised provisions should enhance the relationship between the UAP's and the basic D.D. program, as well as provide clearer direction for the continued operation and expansion of the UAP's themselves.

Last, but certainly not least, is NARC's continued support of Part D, the Special Projects Grants. The restructuring of this Part will make the Special Projects more directly supportive of the State Formula Grant Program. Our organization is currently administering the Federal Programs Information and Assistance Project, a D.D. project of national significance in concert with the three other organizations represented on this panel (Epilepsy Foundation of America, National Society for Autistic Children, and United Cerebral Palsy Association) testifying before you today. This project is typical of the important activities that can and are being carried out to support D.D. Councils and advocates working on behalf of our developmentally disabled citizenry. This part should be continued as revised.

In closing, Mr. Chairman, I wish to reiterate the National Association for Retarded Citizens' continued support for the D.D. program and particularly for your bill, H.R. 11764. If enacted, it will represent a major, forward step in enhancing the lives of our developmentally disabled citizens. The 300,000 NARC members commend you and urge you to expedite the passage of this legislation in order that the D.D. program is extended in accordance with the timetable of the Congressional Budget Act.

We thank you and members of the Committee for your continued interest and support.

Mr. Rogers. Thank you very much, Mr. Smith, for highlighting your statement for us and giving us a clear idea of the points you are most concerned with.

Mr. Smith. Thank you.

Mr. Rogers. Dr. Helsel.

STATEMENT OF ELSIE D. HELSEL, Ph. D.

Dr. Helsel. I think if I can bring you something you need, this wonderful information and all these data you have been gathering today, it might be a perspective from a varied point of view. I have been privileged to look at this program as it operates from all kinds of points. I am the parent of a 30-year-old severely disabled son, which got me into working for cerebral palsy.

I am here representing United Cerebral Palsy Association today as chairperson of their governmental activities committee. I have had a few other chores. I was chairperson of my State DD council in those early years and served on it for 6 years. Now, I am directing a university-affiliated program back at Ohio University. I wish it were in Florida. All winter long I wished it were in Florida.

I have had an opportunity to look at this program and see how some of the theoretical parts of it impact when you get down to the grassroots and start delivering service. So, what I have to say will come from that point of view.

First of all, from the United Cerebral Palsy point of view, I do want to thank you very, very much, and we are enthusiastically endorsing this legislation. Particularly, I am pleased that you took the version that voluntary groups were able to forge out with a great deal of effort and a great deal of time and sometime with a good bit of stress.

The fact that they were able to get their act together to mediate their differences and to come out with a version which they felt was good and to have you introduce it makes us feel very good indeed.

I will limit my remarks here. My statement is concerned with three primary areas. I just want to touch on some personal examples that I think may be helpful to you.

Particularly, we would like to concentrate on the definition of the developmental disabilities, the planning service relationship which still seems to be a little fuzzy and the role of the State DD councils.

Just in passing, I do want to say that I endorse particularly—I do not know that I can say I am doing this for United Cerebral Palsy—the new section IX you have on the university-affiliated program. The setting of standards and setting of the mission and developing of criteria for new UAF's to come aboard, I think, is a real step forward.

Just a few other points about the definition now. You have heard a lot of pros and cons. If I am going to vote, I am voting on the side of the majority. I think that is what you will find as you move along with the panel here. However, I had the privilege of chairing one of those task forces that evolved the definition that looked very much like the one that finally came out.

I need to share with you that there was not the disparity of opinion concerning what the definition should look like and what it should do as seems to be appearing in the vote. People were really of a pretty single mind. They differed in what they thought was politically feasible. That is the important point that you need to carry with you.

I want to point out something else, too. We feel that with that definition we have defined a unique population that has unique needs. Now, in the Senate version of the bill, this does not appear. It looks as if there are no unique differences among disabled people. Please remember that the nature of the disability differs across the continuum.

In my problems of trying to implement programs for disabled individuals at the local level, where we have had an opportunity to look at the service systems and particularly the service systems that impact on the developmentally disabled population, we find that they have a lovely ivory tower bureaucracy but the bureaucrats did not talk to each other until you get up to the Cabinet level of the Government.

When you have a population that has to draw on services from each of those agencies you are in trouble. This is where the Developmental Disabilities Act has an opportunity to have an impact on coodination of services. You can identify discrete populations.

This developmentally disabled population does have need of many service systems and there are problems out here that unless you have something like this—a targeted program and a State DD council—it is just not going to come together.

You do know that UCPA's national board of directors did endorse the ABT definition. We had only one lady voting not in favor. So, if you are counting up the score, it was heavily in favor of the majority report.

I would like to also refocus your attention on the part of the definition that says that you must have substantial functional limitations in three or more of the following areas of major life activity. This is the thing that got picked up in the Senate version with only two of those areas impacted and it just decimates the intent of the definition.

A final word about a functional definition versus a categorical definition. As I try to teach students, and this is part of my role at the university also, and we come to how you educate the severely and multiply involved individuals, the labels you put on them do not help those students one bit.

Mentally retarded, cerebral palsied; I do not care what it is, what they want to know is what can that child do and what can he not do and what do I have to know in order to be able to manage him?

Our second major point concerns the planning and the service relationship problems with the Developmental Disabilities program. People never seem to quite accept the fact that this is really planning legislation and it is service legislation only insofar as we are filling gaps. No matter how many times you say it, they think if we add more people, that is more service and more money.

I agree it does cost a little more to plan for more groups but not a tremendously great amount. So, if you can keep the language so that that planning is a flexible planning—as you suggested they do differ—so that they do have the opportunity to do their own thing in their own way, yet pick up the targeting idea on the major service areas that have been identified and documented both by the private associations and a recent DHEW contract study. I think this will be a great improvement on the legislation.

One of those areas on which we have asked that funding be targeted I would like to say a little bit about, and that is the individual client management services. I would like to suggest some different language for that. Instead of client management services, which sounds a little manipulative, I suggest that you talk about coordinating services rather than management services. Individual client program coordination services which will do the same thing that you have outlined in your definition in your bill, provide access to the consumers, provide follow-on services and provide coordination, but place a responsibility level for that coordination.

Developmentally disabled individuals with their many service needs have many case managers. So, it is not a case management system you are looking for. You are looking for somebody who can pull those programs together and be responsible for them.

One little last remark on that point; namely, something that seems to have been dropped out of H.R. 11764. UCPA would like to suggest that in section 11(b) you put a new subsection which in essence would provide for an additional service category chosen by the State council if the State can document to the Secretary that the four primary service priorities have been met.

This would allow States, who are already doing their thing and doing it well and have those four areas covered, a flexibility posture in order to choose some area that they feel is important.

Now, last, the role of the State council. Obviously, I have been a chairman of a council; they are very dear to my heart. I think they do a very good job. I have seen them take a large State like Ohio and have some impact on a very, very well entrenched bureaucratic system. They can work.

I agree it is a little bit dependent on personalities and people who are determined that things work, but I think there are lots of folks like that out in our Nation. They do need more time in order to show how to impact on their system.

Particularly, I would like to compliment you on insisting in your bill that at least one-sixth of that State DD Council membership be persons with developmental disabilities or with a milder form of developmental disability. I think that it is really very, very important at this time in our history that we do have more input from consumers. They have something to tell us and we should make it possible for them to do that.

Now, in closing, I hope you remember that enthusiastic applause you received last April, during your keynote speech before UPCA's annual conference, when you stated that:

> The bill will need renewal next year by May 15, and I want you to know that our committee will address itself to it. We will meet the deadline. We will extend the legislation by May 15 of next year.

UCPA commends your sincerity and your keeping of this pledge. Our Nation's citizens with developmental disabilities are deeply indebted to you.

Thank you.

[Testimony resumes on p. 206.]

[Dr. Helsel's prepared statement follows:]

STATEMENT

RESPECTFULLY SUBMITTED TO THE
SUBCOMMITTEE ON HEALTH AND
THE ENVIRONMENT
OF THE HOUSE COMMITTEE ON
INTERSTATE AND FOREIGN COMMERCE

ON

H.R. 11764, THE "DEVELOPMENTAL
DISABILITIES ACT AMENDMENTS
OF 1978"

ON BEHALF OF

UNITED CEREBRAL PALSY ASSOCIATIONS, INC.
THE CHESTER ARTHUR BUILDING
425 "EYE" STREET, N.W., SUITE 141
WASHINGTON, D.C. 20001

APRIL 4, 1978

U.C.P.A. Governmental Activities Office Washington, D.C.

INTRODUCTION

Mr. Chairman, my name is Elsie D. Helsel. As a parent of an unserved severely disabled son, Robin, I have been a volunteer with United Cerebral Palsy Associations, Inc. for over twenty-five years and am currently chairperson of UCPA's Governmental Activities Committee. I have been a former chairperson of the Ohio Developmental Disabilities Planning Council and currently am the director of the University Affiliated Center for Human Development at Ohio University.

My son, Robin, is a young man multiply disabled by cerebral palsy, mental retardation, and epilepsy. He is typical of many persons to whom we refer as developmentally disabled, and he is the reason that I worked hard in 1969 and 1970 in advocating for the establishment of the Developmental Disabilities Act.

United Cerebral Palsy Associations, Inc. is pleased enthusiastically to endorse H.R. 11764, the "Developmental Disabilities Act Amendments of 1978." We are honored that you have proposed legislation based on recommendations of most of the organizations associated with the Consortium Concerned With The Developmentally Disabled (CCDD). These recommendations grew out of months and months of deliberations in the private sector. In June, 1977 the national presidents, executive directors, governmental activities chairpersons, and governmental activities directors of UCPA, the Epilepsy Foundation of America, the National Association for Retarded Citizens, and the National Society for Autistic Children met and agreed on a conceptual framework for extending the DD legislation. This was followed by a CCDD Washington staff issue paper, a follow-up meeting in September, 1977 of EFA-NARC-NSAC-UCPA governmental activities volunteer and staff, a finalized staff issue paper on October 20, 1977, and finalized proposed language for renewal of the DD Act on January 25, 1978. Since then, ten national organizations which participated in the CCDD negotiations have endorsed the proposal now known as H.R. 11764.

This CCDD process demonstrates one of the true accomplishments of the DD program - cooperation. By highlighting the common needs of persons with severe disabling conditions originating in childhood, the DD program has encouraged close working relationships between organizations of consumers, parents, volunteers, professionals, service providers, advocates, and state government officials. The DD program symbolizes this new spirit of cooperation. H.R. 11764 proposes modifications which will make the program more viable both at state and federal levels.

Other than the definition of developmental disability itself, there is little new UCPA can say, Mr. Chairman, that has not already been conveyed to you. Our Washington office director was a primary draftsman of both the October 20, 1977 staff issue paper and January 25, 1978 proposed legislative language which you have already reviewed. UCPA's testimony will concentrate on three fundamental areas:

1) The Definition of Developmental Disability

2) The Planning/Service Relationship

3) The Role Of The State DD Council

As a director of what we now refer to as a "university affiliated program," I would like to say that I particularly endorse Section 9 of H.R. 11764 (pages 16-21 of the bill) which amends the UAP program. The inclusion of a national UAP mission statement and the requirement that all UAPs meet nationally - promulgated standards of excellence will encourage closer service-training-research linkages throughout the nation.

THE DEFINITION OF DEVELOPMENTAL DISABILITIES

Mr. Chairman, UCPA has actively supported the evolution of the "developmental disability" concept, which targets attention on those severely disabled persons whose handicapping condition occurs early in life. We have long maintained that without a deliberate and specific service focus, this population goes unserved.

The developmentally disabled population is characterized by factors of early onset of disability, severity, multiplicity of disabling conditions, and neglect. As a result of the early onset factor, individuals thus disabled have substantial difficulty compensating for their disabilities because they lack prior experiences of normal growth and development. These persons require a multiplicity of comprehensive services requiring individual, family, and professional attention. This target population has historically been neglected by existing generic service systems - they traditionally reside at home or in segregated institutions and are too difficult to serve in specific goal-oriented, time-limited programs such as Vocational Rehabilitation. Because of the nature of their disability, many persons who are developmentally disabled have experienced discrimination which diminishes their quality of life.

UCPA is proud that we have been in the forefront of advocating a functional orientation to the problem of severity of handicap and developmental disabilities. In its 1969 and 1970 Congressional testimony on DD UCPA emphasized the functional similarities between mental retardation, cerebral palsy, and epilepsy. At the first national conference on developmental disabilities, held in Washington, D.C. in 1972, UCPA publicly declared the need for a functional definition of developmental disability. This advocacy position has been repeated at every Congressional hearing at which UCPA has had the occasion to testify since 1972.

In its October, 1977 executive committee meeting, UCPA's National Board of Directors endorsed, with one objection, the definition of developmental disability developed by Abt Associates:

> For purposes of the Developmental Disabilities Act, a developmental disability is a severe, chronic disability of a person which:
>
> 1) is attributable to a mental or physical impairment or combination of mental and physical impairments;
>
> 2) is manifest before age 22;
>
> 3) is likely to continue indefinitely;

4) results in substantial functional limitations in three or more of the following areas of major life activity:

   a) self-care,

   b) receptive and expressive language,

   c) learning,

   d) mobility,

   e) self-direction,

   f) capacity for independent living, or

   g) economic self-sufficiency; and

5) reflects the need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are

   a) of lifelong or extended duration and

   b) individually planned and coordinated

This definition reflects the belief that it is the severity of impairment and the long term nature of the disability and consequent need for multiple services, usually for a lifetime, which should be the basis for the definition, rather than etiology of diagnostic category. "Mental or physical impairment" is intended broadly and is meant to include all neurological, sensory, biochemical, intellectual, cognitive and affective impairments.

The definition that evolved from the Abt Task Force represents the best thinking of individuals who have worked with the developmentally disabled over a long period of time and hopefully have a repository of knowledge and expertise equal to the task of defining the population. The three meetings of the Task Force were very productive and the definition represents the best thinking of a majority of the group. It should be pointed out that there was no disagreement in the group concerning a functional definition such as the one voted by the majority of the group. The disagreement was a political one based on what would be politically feasible and administratively possible at this point in time. The majority of the group felt that further labeling is discriminatory and does not focus on the functional needs of developmentally disabled individuals.

THE PLANNING/SERVICE RELATIONSHIP

The original DD Act recognized that the priority needs of the target population varied significantly from state to state and attempted to give states maximum flexibility to address its needs through a combination of service, planning, and systemic advocacy activities. In practice, few states have achieved progress in striking a balance between these various roles, and few states can document how they have impacted significantly on the service system within the state.

A DHEW Developmental Disabilities Office (DDO) contract analysis of fifty-four 1978 State DD plans demonstrates that states have been able to access other program funds for needed services. The rate of non-DD funds generated by DD dollars follows:

Category	Non DD Dollars Accessed By DD
Institutional Reform	$14.60 for every $1 of DD funds spent
Prevention of DD	$13.10 for every $1 of DD funds spent
Service Coordination	$ 1.50 for every $1 of DD funds spent
Community Alternatives	$ 1.40 for every $1 of DD funds spent
Promotion of Standards	$ 1.20 for every $1 of DD funds spent

DDO concludes that in addition to the required State matching for FY 1977, over $2 million or 6% more dollars have been spent on DD.

The DDO study identified numerous gaps in services, including individual client program coordination (case management, follow-along, and coordination), preschool and adult education and training, employment, identification, and residential services. The major program gaps identified in the F.Y. 1978 state plans were deinstitutionalization/community alternatives, public awareness, adult programs, individual habilitation plan development, and provision and improvement of services. Given these gaps, it is interesting to note that over 50% of the states established goals for deinstitutionalization, prevention and early intervention, quality of service, community alternatives, and coordination/systems advocacy.

H.R. 11764 attempts to continue state planning efforts while recognizing that the ongoing filling of service gaps is an outcome of planning, and that significant impact by the program is most likely if service activities are focused on a limited number of nationally-identified priority areas. In this regard, UCPA particularly endorses:

(1) Section 11(b)(4)(A)(iii): hold-harmless provision to insure that no state receives a lower planning allocation than that awarded for this fiscal year.

(2) Section 11(b)(2)(C): targeting the filling of state service gaps specifically on "individual client management services," "infant development services," "alternative community living arrangement services," and "nonvocational social-developmental services."

UCPA fully supports the definition, concept and priority given to "individual client management services;" however, in this era of self-actualization and independent living objectives we prefer to see the management idea replaced by the coordination concept.

An individual client program coordination service attempts to assure a comprehensive continuum of services by providing consumers with access to existing service systems. The process involves the dual concepts of follow-along (providing for a continuing relationship with the client on a lifelong basis if necessary, for the purpose of assuring that changing needs are recognized and appropriately met) and coordination (process by which responsibility for implementation of the client's individual program plan is established). A developmentally disabled person has several case managers. What he lacks is somebody to develop a systemic approach to services and assume responsibility for following the individual along, advocating where necessary on his/her behalf, for the rest of the consumer's life. As we design a system to encourage deinstitutionalization and prevent unnecessary institutionalization, we should look to individual client program coordination as the gatekeeper.

The DDO study also identified lack of funds for program expansion (over 50% of the states) as a major barrier to a state's ability to have a significant impact on services. For this reason, UCPA strongly endorses the Section 131 increases in state authorization levels.

Lastly, there was one CCDD recommendation dropped in H.R. 11764 which UCPA believes should be restored in order to grant states a little more flexibility in the service area. UCPA suggests that Section 11(b) of the bill be amended to include a new subsection (8):

> "provides for an additional service category chosen by the state council if the state can document to the Secretary that service priorities in Section 11(b)(2)(C) are fully met in that state."

THE ROLE OF THE STATE DD COUNCIL

Those of us associated with the voluntary movement in this nation firmly believe in the necessity of private citizen advisory panels to monitor and influence the operation of governmental agencies. The principle of open government necessitates meaningful input by parents and consumers.

The mechanism of the Developmental Disabilities Planning Council, with the required representation from state agencies serving the handicapped, voluntary groups concerned with the handicapped, plus consumers and parents, has had many spin-off benefits. The Council meetings have become forums where state agency personnel can interact productively with staff from other state agencies serving the developmentally disabled. These public agency representatives also are confronted with representatives of voluntary agencies serving the handicapped and with consumers themselves. Together these representatives have learned to address problems to coordinate efforts, and to appreciate the impact, or lack of impact, their programs have on persons with disabilities.

DD Council activities have had a therapeutic effect on the relationships among the voluntary agencies as well. Prior to DD, voluntary agencies were frequently in competition for attention and funds, both at the federal and state levels. DD has clarified the advantage to the voluntary agencies and the clients they serve of coordinating efforts, and sometimes even joining forces in order to launch new programs.

Some State DD Councils are successful models for effectively influencing the allocation of generic resources and changing the behavior of major statewide delivery systems. All State Councils have the potential for encouraging state agency interaction in order more fully to integrate system delivery. UCPA strongly endorses the proposed State Council responsibilities outlined in Section 12 of the bill.

The DDO study documented that nearly 2/3 of the states cited coordination of services as a barrier to service provision. The DDO contract study concluded that "the needed continuous services for persons with developmental disabilities either do not exist or are inadequate due principally to the lack of interagency communication." Over 70% of State Council activities involved service coordination and improvement of the service system. It is important to note that approximately 40% of the funds for State DD coordination activities were provided by other sources.

Lastly, UCPA has undertaken significant internal changes over the past few years predicated upon a commitment to ensuring consumer involvement at every level of our organization. The establishment of a Consumer Activities Committee staffed by disabled persons as a standing committee of the national board of directors attests to our commitment. UCPA is thus very pleased to see Section 12 require that "at least one-sixth" of the State DD Council membership" shall be persons with developmental disabilities or with a milder form of such disability."

CONCLUSION

Mr. Chairman, we trust you will recall the enthusiastic applause you received last April, during your keynote speech before UCPA's annual conference, when you stated that

> "...the bill will need renewal next year by May 15, and I want you to know that our Committee will address itself /to it/. We will meet the deadline. We will extend the legislation by May 15 of next year."

UCPA commends your sincerity and your keeping of this pledge. Our nation's citizens with developmental disabilities are deeply indebted to you. Thank you.

Mr. ROGERS. Thank you so much. Thank you for being here. That is a second call to the floor for a series of votes. It will take about 20 minutes, I am afraid. I might say to witnesses who are to come, if you could be looking over your statements so that you could have the highlights underlined to give us quickly. We want to get to everyone this afternoon, but we have a whole page of witnesses still.

If you can do that for us, it will be helpful. The committee will stand in recess for 20 minutes.

[Brief recess.]

Mr. CARTER [presiding]. The subcommittee will come to order. Ms. Akerley.

STATEMENT OF MARY S. AKERLEY

Ms. AKERLEY. Mr. Carter, I am very happy to be here. My name is Mary Akerley. I live in Maryland. I am a mother of a 12-year old who has autism. So, I have the perspective of a consumer in speaking on developmental disabilities.

In addition, for the last 2 years, I have been a member of the Maryland State Council on Developmental Disabilities, not as a consumer but as provider. I am the assistant executive director of a private, nonprofit agency serving handicapped people. We serve over 300 people, all with varying kinds of disabilities.

So, when I hear that we must be very precise in the definition and spell out exactly who is included and who is not, I am not entirely sympathetic with that. I think we have a very good service program where we are able to integrate people with various kinds of disabilities according to service needs and I know that works.

I am also an active member of the Consortium Concerned with the Developmentally Disabled. Obviously, I am very happy to enthusiastically support your bill, to support it as an individual and as a spokesperson for the National Society for Autisic Children. I, too, will condense my remarks and I will from time to time respond to some of the things that have been said earlier, particularly remarks that were made this morning.

I believe I share the Chair's impatience with the administration and their desire to defer any kind of substantive action on this legislation. Clearly, we need a developmental disabilities program. You have heard that theme since you started at 10 o'clock this morning.

I think we need some changes in it. It is not a perfect program. We who have been working with it as providers and as consumers at State and national levels have been able to pinpoint what some of the problems are. We have been able to devise renewal legislation that addresses these problems.

Then, to hear the administration say, "We need to know what must be done," and that is a direct quote, I wrote it down when the Commissioner said it, and in the next breath say that, "The service needs are similar" makes one wonder what one is really hearing.

Obviously, nothing in this bill is going to hurt anyone. So, why do we need to be so fearful of tightening up the program and making some substantive changes?

We were also asked this morning to address ourselves to S. 2600 and I will be happy to do that.

It is a beautiful bill. It looks like a Christmas tree. However, I am afraid there will not be enough power in the house to light all the lights on the tree. The levels of funding called for in the bill are exciting; the services called for are exciting. One needs only to look at the history of funding of the DD program to know that inspite of all that excitement, nothing is going to happen.

There is no way that once beyond your control or the subcommittee's control that you can assure that level of funding. I do not think a bill that calls for a vastly extended population and this whole smorgasbord of services is the way to meet the needs of our people.

Our people are the hardest to serve and the most expensive to serve. When the money runs short, they will be the ones underserved.

The points that we make in our prepared statement are four, and I will highlight them. One is the definition. The second is the composition of State council. The third is the protection and advocacy system and the fourth is the issue of targeting.

Relative to the definition, you may have picked up that the Autistic Society is supporting the majority report. They have formally endorsed that.

Mr. Chairman, I was here 3 years ago. Then I was the future president of the Autistic Society. You chaired the hearing. We were talking about the same issues. I think it was the same room. The only difference was at that time autism was not included.

My memory is not so short that I cannot remember what it was like to be excluded from a system that could have helped my child and other children like him. I could not in conscience sit here today and support a definition that would do that to other children. I think it is very interesting that members of our board in voting last month on this definition made exactly the same point.

You were kind enough 3 years ago to compliment me about my testimony. I think you probably remembered some of the points I made because I am told that you referred to them in the markup session. I asked then, and I am going to ask it again, how we can decide to serve a child with a certain set of needs because he has brain damage and turn our backs on his peer with the same needs because that child has spinal damage.

Those kinds of decisions are unethical. They are based on the power, the political power, and the sophistication of the advocates. They are not based on equal right to care. So, I would suggest to the subcommittee that they support the majority definition.

I know the minority report says the listing of disabilities is simply to give examples. They are touchstones for us. They said that in 1970, and my kid did not get served until 1976. So, I really cannot go along with, "These are just examples."

People do not read them that way. They look and they say, "This is the prescription." The more firmly you include certain disabilities, the more firmly you exclude the ones that are not mentioned. I think that is a real danger with the minority report. Philosophically, they are certainly very, very similar.

I was sensitive to the comments of the people who spoke on the minority report and I would just like to say that if the State of Wisconsin has to review all its laws, that is too bad. All the people with spina bifida and osteogenesis imperfecta will be affected. And Wisconsin can review its law with a computer.

Relative to the composition of the councils, we are certainly very pleased to see the evolution of our thinking as is reflected in this legislation. One point that has not been addressed today that I feel is very important is the composition of the national council.

The bill, of course, recommends an expansion of the ex officio members. We think this is important. It reflects the changes that section 504 is making in agencies beyond HEW. We think this will lower the barriers to service, not just for the DD population, but for all the handicapped. We will have those people working with us in redesigning their programs.

We would like to call the subcommittee's attention to a technical omission in the bill and it is the Consortium's fault. I will say that in public and for the record. The provision that the secondary consumers on the State councils, that is the parents or relatives, include someone who is the relative of an institutionalized person is not included in the language on State councils, and it should have been.

Now that was left out of the consortium draft. I looked back over it and saw it, and we apologize. We ask that you restore the language that you have for the national council to the section on State councils.

I would like to say a word about the P and A systems. We are certainly not looking to programmatic changes. Those systems have been active only 6 months. They are awfully important. People with developmental disabilities have legal needs that are not quite the same as the so-called normal population because there are a lot of legal and ethical issues that surround service to them that do not obtain for the rest of the population, so that they need a strong system to look after their rights.

P and A systems could be that if they had adequate funding. Yet, no one has mentioned it, so I will take the liberty of doing so, that the HEW guidelines for these systems create a potential "catch 22" in that they require the P and A systems to seek out their own sources of additional continuing funding. I do not know any P and A system that is overstaffed. I do not know anyone that has a fundraiser on its staff.

What this means is that the director of the system, who hopefully was selected because he or she was a good advocate, is going to divert some of the advocacy time to fundraising. I think that is harmful. I hope we are not back here 3 years from now to hear the P and A systems criticized because they did not do enough advocacy.

So, I think it is awfully important that the funding at the Federal level be raised. Certainly, the levels in this bill are an absolute minimum.

Finally, I want to talk about targeting because I know that has become rather controversial. We know some people feel the recommendations of targeting by age and service categories are very limiting and that it is taking away from the State's rights. I do not feel that that is quite true.

First of all, we have never had the promised evaluation. We were concerned about this and felt targeting might assist in a sane evaluation of this program, if you could sharpen the focus of it, have national goals, and tie in State service priorities to those goals.

Right now, the State can pick any kind of emphasis, pick from a menu of 16 services and pick the one it wants. We think the targeting will take care of that.

We also would like to point out that the areas for targeting are very broad. They still give the States a lot of flexibility and they do all lead to deinstitutionalization. We feel that targeting by age will satisfy another criticism that the program is duplicative, say, of the Vocational Rehabilitation Act or Public Law 94–142 because deliberately this bill says, "No, we are going to help the people who are not covered now by existing systems for the handicapped."

In summary, Mr. Chairman and Mr. Carter, our organization is most appreciative of your interest in and support for this program. It has meant a lot to our sons and daughters. We appreciate your sensitivity and responsiveness to their needs.

Thank you for sponsoring H.R. 11764 and for giving us this opportunity to speak on it.

[Ms. Akerley's prepared statement follows:]

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Dedicated to the education and welfare of children with severe disorders of communication and behavior

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STATEMENT ON
H.R. 11764
"THE DEVELOPMENTAL DISABILITIES ACT AMENDMENTS OF 1978"

RESPECTFULLY SUBMITTED TO
THE HOUSE SUBCOMMITTEE ON
HEALTH AND THE ENVIRONMENT
APRIL 4, 1978

BY
MARY S. AKERLEY

NATIONAL SOCIETY FOR AUTISTIC CHILDREN
169 Tampa Avenue, Albany, New York 12208 518/489-7375

STATEMENT ON H.R. 11764
April 4, 1978

Mr. Chairman and Members of the Subcommittee:

I am Mary Akerley, a past President of the National Society for Autistic Children and the mother of a twelve-year-old son with autism. For the last two years, I have been a provider member of the Maryland Developmental Disabilities Council (I am the Assitant Executive Director of a private, non-profit service agency for the handicapped); so I have the advantage of several perspectives on DD.

I am also an active member of the Consortium Concerned with the Developmentally Disabled, representing NSAC on that body. Obviously I as an individual, and as NSAC's spokesperson, enthusiastically support H.R. 11764 and appreciate this opportunity to advise the Subcommittee of our views on DD renewal.

At its recent winter meeting, the Board of Directors of the National Society formally endorsed both the CCDD renewal proposal and the Abt majority report on the definition of developmental disability. Our position has always been that a non-categorical definition which retained the concepts of early onset and chronicity, and not only retained but emphasised the concept of severity, would be more precise as well as more equitable than the present definition. Mr. Chairman, some three years ago I appeared before this Subcommittee, representing the same organization, to testify on the same subject. The big difference between today and that earlier hearing is that, back then, autism was not officially recognized as an eligible disability. My memory is not so short that I have forgotten what it was like to be excluded from a system that could help my child and others like him.

And if your memory is as long as mine - and I suspect it is - you may remember some of the things I said three years ago. You were kind enough to compliment my statement after the hearing, and I am told you made reference to my points about the definition during the mark-up sessions. I asked then how one could decide to serve some physically handicapped children solely because their impairments resulted from brain damage and simultaneously exclude other children whose needs were virtually identical because their handicaps came from damaged spines. I said such thinking was at best inefficient becaue it led to either dual service systems or, more likely, to lack of services for some; at worst it was unethical because it meant people would be served on the basis of the political power and sophistication of their advocates, rather than on the basis of their equal right to care.

Clearly, you and other members, not only of this Subcommittee, but of the entire Congress, were sensitive to this injustice because, while you mandated the inclusion of autism, you went beyond that to require an impartial study of the definition. I was a member of the Task Force that -

literally - agonized over the formulation of a definition that would insure fairness to a very specific population: those whose development was so impaired by internal factors that they would require multiple services throughout their lifetimes. It is to the credit of the Task Force that, despite almost no representation for conditions not included in the present definition (of the forty-seven members, only four could be viewed as representing the "outs"), the majority were able to ignore parochial concerns and recommend wording that got to the essence of who it is we are trying to help.

With all due respect to you, [illegible]airman, I do not believe the Abt Task Force's recommendation is a "relatively significant expansion" of the present definition, at least as regards to numbers. Rather, by clarifying the issue of severity, the Task Force offset any increases due to the removal of categorical limitations. At present, because the crutch of diagnostic categories is available, the level of severity is not universally considered in implementation strategies. In other words, DD is presently regarded as for *all* those who have retardation, cerebral palsy, epilepsy or autism, which was not the original intent any more than it is the present intent.

The functional approach taken by the Task Force does, of course, relieve us of the horror of having to make arbitrary distinctions between etiologies. In that, it *is* a "relatively significant expansion," Mr. Chairman; you are right. And for that very reason, it is the definition Congress should adopt.

The changes recommended in the composition of the Councils - National and State - underscore the DD focus on multiple services and on consumer involvement. Both reflect a welcome evolution in the thinking of those who make decisions affecting the handicapped. The specific inclusion on the National Council of federal administrators beyond HEW programs illustrates the effect Section 504 has had, and should facilitate rapid elimination of barriers to the use of generic service programs by not just the developmentally disabled but by all handicapped citizens.

The refinement of the definition of handicapped consumer members of Councils is official recognition that a disability in and of itself does not preclude a person's assumption of social responsibility, for himself and for his peers. It is an acknowledgement that, whenever possible, disabled persons are their own best advocates; while simultaneously insuring an equal voice for those often bypassed, and giving that voice to those most qualified to speak in it.

We do need here to call the Subcommittee's attention to a technical omission in the section on State Councils. The secondary consumers on those Councils should include at least one representative of the institutionalized population. Not only are their service needs and service delivery mechanisms somewhat different from those of disabled persons in the community, they are the disabled most vulnerable to abuse and to abridgement of their legal and human rights. Moreover, such representation is consiste[illegible]h the mandate for deinstitutionalization and institutional reform. Therefore, the National Council requirement that, of the consumer representatives for the mentally impaired, at least one be the immediate relative or guardian of an institutionalized person should be added to the relevant section on State Councils.

In reviewing the draft the Consortium submitted to the Subcommittee, we did note that the omission was ours; we apologize for that, and ask that the wording, "at least one of whom is the immediate relative or guardian of an institutionalized person with a developmental disability," be added to Section 137 (a) of the bill after the words "mentally impairing developmental disabilities" (page 28, line 14).

While no programmatic changes are suggested for the Protection and Advocacy systems, we do wish to emphasize their importance in the lives of developmentally disabled persons. There are legal and ethical issues concerning the rights of the developmentally disabled and their families which are by no means clear-cut, and which are very different from those affecting "normal" people, particularly when one is confronted with cognitive and judgemental impairments. Clearly, public advocates with both a knowledge of law and a sensitivity to the effects of disability are needed to protect this population and insure their equitable treatment.

We therefore urge the Subcommittee to retain the increased authorization levels for P & A systems in H.R. 11764. The P & A program is, as you know, only just getting underway. These systems have been operating only six months; most are already concerned with future funding. Unfortunately, the HEW Guidelines created a potential "Catch 22" for the P & A systems by requiring them to seek out sources of continuing support. No P & A system is overstaffed; none, to my knowledge, includes a fundraiser. Hence, the Director, who was - hopefully - selected for his or her advocacy skills, is going to have to devote some time to raising money, time that therefore cannot be spent on advocacy. I hope that, three years from now, we will not be hearing the P & A systems criticized because they didn't do enough advocacy. The realistic authorizations of H.R. 11764 (if realized) will alleviate that dilemma considerably.

Finally, NSAC wishes to address the issue of "targeting." We are aware that there is some feeling that specifying certain age groups as having priority and limiting the allowable services to the four mentioned in H.R. 11764 is too restrictive, that it takes away from the flexibility the states presently enjoy under DD. However, we are also aware that there is even stronger feeling - some of it in official circles - that the program has never been properly evaluated, and probably cannot be as it is presently designed.

Targeting by age and service will give the DD program needed focus and, by virtue of that focus, a basis for evaluation. At present, states may choose one or several areas of emphasis from a menu of sixteen services without any reference to national goals or priorities. Consequently, the kind of comparative data (both intra- and interstate) needed for evaluation is virtually unobtainable. Stating national objectives and tying local efforts to them will give the entire program a cohesiveness that is presently lacking. This will be achieved without any real loss of local options because the four priority categories are broad enough to permit a wide range of services, no matter which one is selected. And, despite our emphasis on services, we do support the provision which permits a state to continue its planning efforts at the present level.

Targeting by age will eliminate the possibility of duplication of service; even with P.L. 94-142 and the 1973 Rehabilitation Amendments we need DD, and the new language insures that those not covered by the major service legislation for the handicapped would receive needed attention.

In summary, Mr. Chairman, the National Society for Autistic Children is very appreciative of your interest in and support for this program, which has meant so much to our sons and daughters. We appreciate your sensitivity and responsiveness to their needs. Thank you for sponsoring H.R. 11764 and for giving us this opportunity to speak on it.

Mr. **Rogers.** Thank you, Ms. Akerley. We are pleased to have you with us.

Mr. Flannery.

STATEMENT OF LEO FLANNERY

Mr. **Flannery.** Mr. Chairman and members of the committee, my name is Leo Flannery. I am from Florida. I am pleased to be speaking today on behalf of the Epilepsy Foundation of America.

It is the foundation's position that the developmental disabilities program is the most effective instrument for promoting the delivery of comprehensive services that has appeared to date for people with epilepsy.

As the national grassroots voluntary agency concerned with epilepsy and as a member of the Consortium Concerned with the Developmentally Disabled, the foundation strongly supports H.R. 11764. It is the foundation's position that many of the changes in the renewal legislation will bring about substantial progress in the planning and provision of services to the developmentally disabled.

Mr. Chairman, I know first hand what epilepsy means. Four of my five children have myoclonic seizures, a very serious and, in our case, degenerative form of epilepsy. My wife and I have devoted the past decade in trying to bring our childrens' seizures under control.

As you may recall, Mr. Chairman, your office arranged for neurological evaluations of four of my children at the National Institutes of Health.

At that time, the medical community did not feel that there was too much that could be done. I also know first hand what the Developmental Disabilities Act has meant to persons with epilepsy. I was a charter member of the Florida Developmental Disabilities Council as well as the first president of the Florida Epilepsy Foundation. I have seen the developmental disabilities program in action, and I know what it has meant for people with epilepsy in Florida.

Before epilepsy was included in the Developmental Disabilities Act, people with seizure disorders were a neglected population in Florida, as they were in most other States.

But once it became included in the act, epilepsy had a forum through which the needs of this population could be brought to the attention of State officials. A statewide conference on epilepsy was conducted, funded with DD dollars, which pointed out some of the really glaring deficiencies and oversights in the State's human services program as they related to persons with epilepsy.

As a result of this conference, the secretary of the department of health and rehabilitative services in Florida authorized a task force composed of public and private agencies, as well as consumers, to prepare a 5-year action plan for epilepsy in the State.

The plan was subsequently developed, and many of its recommendations have been implemented. I should like to mention just a few of these. Because of the plan which DD made possible, over one-half million dollars in annual title XX and State match funds have been obtained, beginning with the year following the completion of the plan.

Training programs were implemented immediately for vocational rehabilitation counselers, thus creating specialists in epilepsy rehabilitation in each region of the State.

Guidelines for teacher training in epilepsy were created and processed through the State department of education into all standard teacher training curricula in the public schools.

Administrative guidelines for drivers' licensing for persons with epilepsy were drawn up which included provisions for due process. There was stimulation of many innovative community service programs, including a long-awaited seizure clinic in West Palm Beach, which not only serves Palm Beach but some of the outlying counties.

I could continue, but the bottom line was that the problems of people with epilepsy were given special focus and attention for the first time.

Mr. Chairman, my point here is simple. By naming epilepsy as a developmental disability, focus was at last given to a population whose needs had been long overlooked. And I feel sure that you will appreciate that it is because of the progress that has been made, largely as a result of the Developmental Disabilities Act, in identifying the needs and providing for the services necessary to the person with epilepsy, that we are most anxious to see this disability continue to be identified in the renewal legislation.

I feel that our experience in Florida and similar experiences across the country suggest several points:

First, if the Congress decides that the act should be expanded and strengthened, then the additional populations to be served should be identified so that they may receive specific attention, as epilepsy did in Florida.

Second, if this is done, Congress should authorize and subsequently work to assure that appropriations are actually made and that they are sufficient to meet the additional needs of an expanded population.

The Epilepsy Foundation of America recognizes that there are a significant number of people who have needs similar to those of individuals who currently meet the categorical definition of developmental disability.

For this reason, the foundation's board of directors has unanimously endorsed the minority report of the National Task Force on the Definition of Developmental Disabilities. It was the position of the 11 signers of the minority report that the definition of developmental disability not be based on the rather vague and all-encompassing phrase "mental or physical impairment."

They urged rather that the existing categorical disabilities named in the act be retained, with a strong emphasis that other individuals whose impairments require services similar to those required by the disabilities named in the definition should also be served.

This approach would meet the need to serve those who are not now diagnosed as developmentally disabled but who have similar needs, while continuing to focus on the special needs of the DD population, needs which the Congress has repeatedly recognized in the drafting and renewal of this legislation in the past.

To summarize, the Developmental Disabilities Act has wrought significant benefits for a long neglected and underserved population.

It has also created a climate in which their needs are finally being recognized by State planning bodies.

The Epilepsy Foundation of America is pleased with the progress made to date and believes that, with the modifications proposed in H.R. 11764, this progress can be significantly accelerated.

I thank you, Mr. Chairman.

Mr. ROGERS. Thank you, Mr. Flannery, for being here. I am glad to hear that your children are doing much better.

Mr. FLANNERY. Thank you.

Mr. ROGERS. I think you have given us very clearly the points you want the committee to have. We will go over them carefully. As we draft, if we have questions we may come back to you for your advice. Thank you for your presence here. It has been most helpful to the committee.

Mr. SMITH. Thank you, Mr. Chairman.

Mr. ROGERS. Now, we have a panel representing the University-Affiliated Facilities. Dr. Phyllis Magrab, president of the American Association of University Affiliated Programs and director of the University affiliated program for child developmental disabilities, Georgetown University Medical School; Mr. Seldon Todd, executive director of the American Association of University Affiliated Programs for the Developmentally Disabled; Dr. Hugo W. Moser, director of the John F. Kennedy Institute, Johns Hopkins University; Dr. Joan Bergman, director of DESEMO, Center for Developmental and Learning Disabilities, the University of Alabama; and Dr. Richard Shiefelbusch, director of the Bureau of Child Research, University of Kansas.

We welcome all of you here. Each of your statements will be made a part of the record in full. If you could highlight the points that have not been covered or have not been made it would be helpful to the committee. We still have another panel to go.

You may proceed.

STATEMENT OF PHYLLIS MAGRAB, Ph. D., PRESIDENT, AAUAP; HUGO W. MOSER, M.D., DIRECTOR, UAP, JOHNS HOPKINS UNIVERSITY, JOHN F. KENNEDY INSTITUTE; JOAN S. BERGMAN, Ph. D., DIRECTOR, DESEMO PROJECT, CENTER FOR DEVELOPMENTAL LEARNING DISORDERS (UAP), UNIVERSITY OF ALABAMA; RICHARD SCHIEFELBUSCH, Ph. D., DIRECTOR, BUREAU OF CHILD RESEARCH, UNIVERSITY OF KANSAS; AND SHELDON P. TODD, JR., EXECUTIVE DIRECTOR, ALL ON BEHALF OF AMERICAN ASSOCIATION OF UNIVERSITY AFFILIATED PROGRAMS FOR THE DEVELOPMENTALLY DISABLED

Dr. MAGRAB. It is out of my professional commitment to the developmentally disabled that I am pleased to present testimony today. Serving the developmentally disabled is not easy. It is a continual confrontation with our own mortality, vulnerability and inevitably our own humanity.

Perhaps it is in this depth of philosophical awareness that we all are here today to speak out on the proposed legislation.

My fellow panelists and I are here representing our association which strongly endorses your bill and we are delighted to see it come forward. In particular, we would like to discuss the university affiliated program portion of that bill to which others already have alluded.

The university affiliated program make available practitioners who can provide diverse and complex services to the developmentally disabled. We have as our major mission the setting of standards of service for this population through exemplary training of professional workers.

There are basically four functions that the university affiliated program provides: first of all, training; second exemplary clinical services in support of that training; third, clinical research, and fourth technical consultation in assisting service agencies and consumer groups.

Because no single professional has all the skills to solve the multiple problems of the mentally retarded or developmentally disabled, it was the wisdom of the Congress to create interdisciplinary training programs that incorporate the functional areas of health, education and social services. Within the university affiliated programs over 50 different disciplines actively participate and most programs have at least a core group of 10 disciplines represented.

The university affiliated program is a national network. This is an important point because by providing leadership training there is a viable exchange of training techniques, of innovative service programs and a mechanism for establishing high standards for the quality of care through this networking process.

The Government in partnership with the academic community through the university affiliated program over the last 14 years has worked toward developing an outstanding manpower base and service delivery program. It continues to be our joint obligation to maintain these programs in sufficient quality to meet the national needs of the group that we serve and to continue to maintain standards of excellence through new knowledge and professional training.

I was going to share with you a case example, which I will not take the time to do now because I think the consumer groups that have spoken before us have typified the multiple needs of the developmentally disabled. The need for training is dictated by the need for services of the developmentally disabled individual and his family.

It is the complexity of the needs of this group that implies the complexity of the training that is necessary. Professionals must be trained in a number of areas, in information exchange, growth and development, community function, diagnoses and assessment, producing change, and interdisciplinary theory and research.

This is a very broad arena. In this broad arena the multiple disciplines must be integrated in their learning; otherwise, the learning becomes fragmentary, isolated and this leads to fragmentary services.

During the last year at Georgetown University UAP, which is a modest size program, not one of the larger programs, we involved over 1,400 students in our training activity with in-depth training for 200 persons. In relation to this training activity we served over 1,500 patients. This was in support of the training endeavor.

Besides the training that occurred within our center there was a strong outreach into the community and this is true across all of the centers in our national network. We have worked with judicial systems in training court workers in handling the developmentally disabled; we have worked with Head Start and day care teachers in the tri-State region and have worked with the developmentally disabled in their settings. We have developed a high risk followup program that has been extended to community hospitals by replication. It is this kind of outreach effort that enhances the services that can be provided to this population.

I now would like to defer to my colleagues who will speak in particular to the service areas, the outreach areas and the kind of training that is accomplished through our networking process.

Mr. Rogers. Thank you, Doctor.

STATEMENT OF HUGO W. MOSER, M.D.

Dr. Moser. I am Dr. Hugo Moser. I am director of the John F. Kennedy Institute for Handicapped Children, which is adjacent to and affiliated with Johns Hopkins Medical Institution. The institute has a 40-bed inpatient unit which serves children with a great variety of developmental disabilities, including mental retardation, cerebral palsy, children in for treatment for lead poisoning, children recovering from head trauma, a variety of birth defects, learning and behavioral defects, and in a very important way children with autism, which was a disorder which was first described by Dr. Leo Kanner at the Johns Hopkins Hospital 40 years ago.

Second, we have a school program which serves also 40 pupils. These are children from the Baltimore inner city referred by the Baltimore School System, who remain for 1 to 2 years. The great majority have then been able to return to regular classroom settings within the public school system.

Third, we serve about 4,400 outpatients a year. So what is so special and important about all this? One, the numbers. We do serve in a comprehensive way a large number of children and their families.

Second, we are a part of a large university and teaching hospital, and I believe that we have had a role as a change agent in shaping attitudes toward the developmentally disabled child. We do this because we have a program which combines medicine, education, behavioral sciences, social sciences in an equal way, areas which are not represented as strongly in the traditional hospital.

We have made, I believe, a considerable impact on changing the attitudes toward the developmentally disabled in a great many health professionals. Our followup program has shown that 80 percent of the professionals who have gone through our training program have made and continue to make a commitment to serving the developmentally disabled after they have graduated from the program

Mr. Rogers. 80 percent, you say?

Dr. Moser. 80 percent.

A third aspect, which has already been emphasized by the others, is that we relate to the community and particularly to institutional programs. We have placed strong emphasis on this. Three of our pediatrics work on a halftime basis, each at Forest Haven, which is the institution for the retarded which serves the District of Columbia.

We have a strong working relationship with Rosewood Training Center near Baltimore. In the latter program we are responsible, together with the State agency, for training direct care personnel toward more effective programs for their clients. In my writeup I gave two examples which I will only highlight in the briefest way.

One of the examples refers to an 18-year-old woman who had, because of outstandingly difficult behavior, been admitted to Rosewood Training Center and under ordinary circumstances, I believe, would have been destined to remain there for the rest of her life.

Together with the Rosewood Training Center program, we have designed a model program, where the young lady spends her days at Kennedy Institute and the evenings and weekends at Rosewood. Her progress has encouraged us to believe that she will be able to return to the community.

This kind of approach is highlighted in a very important way by Dr. Bergman's presentation of her work in Alabama.

Finally, I want to mention one program which I think is particularly important for the developmental disability legislation. This was a program sponsored by the region 3 Developmental Disabilities Office, and coordinated by the neurology staff of Kennedy Institute. In this program Kennedy Institute worked with the UAF's in the other five States in region 3 to develop a program in which each of the clients of residential institutions for the retarded who have seizure disorders, approximately 3 out of 10 residents of these institutions was reevaluated and the seizure disorders were treated.

We found a great many gains in terms of mortality from seizures, the disability caused by seizures, and the vocational and social gains made by the individuals. It is our impression that it would not have been possible to do this without the Developmental Disabilities Act. This is because such a program depended upon the cooperation of the DD Office, of State agencies, of institutional staff, and last but not least the universities. It requires the participation of neurologists, nurses, biochemists to measure blood levels of the anticonvulsant agents, teachers, psychologists, rehabilitation people, and direct-care staffs. I believe that this was by far the most effective way to bring together all these forces and resources for the benefit of so many clients with "double" developmental disabilities who are residents of institutions for the mentally retarded.

Thank you.

Mr. ROGERS. Thank you, Dr. Moser.

Dr. Bergman.

STATEMENT OF JOAN S. BERGMAN, Ph. D.

Dr. BERGMAN. I am Joan Bergman, director of the DESEMO project at the Center for Developmental and Learning Disorders, the University Affiliated Program at the University of Alabama in Birmingham.

Our UAP is also involved in the service and training that my colleagues are speaking of; but it is a provision of technical assistance by a UAP and by, in this case, a special project of a UAP that I would specifically like to discuss with you this afternoon.

DESEMO is an example of a special project offering technical assistance. DESEMO happens to be a product of a very successful linkage of a State mental health department, a UAP, and community programs, and is funded by developmental disabilities money. It was first established in order to demonstrate that an interdisciplinary team of mental retardation professionals, parents, supportive personnel, and consultants could work together to provide a better quality of life for individuals whose handicapping conditions were of such a severity that these individuals required total care.

To see what could be done, we selected 20 severely handicapped individuals who, at the time we started working with them, ranged from 7 weeks to 20 years of age. Not one of these individuals was able to communicate either verbally or nonverbally.

In other words, none had any way of indicating a desire or need or indeed of showing understanding of anything. All had been found to be profoundly mentally retarded as measured with standardized instruments; 10 of these lived in the community and 10 in a State residential facility.

Those living in the community were not receiving comprehensive services. Two had some means of ambulating. Several have severe visual problems and one is deaf. One was tube fed and had no response to any stimulation. One young man has such severe physical deformities that the crest of the pelvis on one side is literally adjacent to the rib cage on the other side, his hands rest on his forearm. The only behaviors exhibited by one is to make rhythmical movements, to make low-pitched sounds, and to bite at anything that comes into his reach.

Several have spent their lives in cribs or crib-like wheeled objects.

Unfortunately, these 20 are representative of individuals who are found on back wards of institutions and for whom the care routinely given recognizes in them no human potential. There is little positive that could be said regarding the quality of life for either these individuals or their parents.

The 20 were deliberately chosen with a wide range of individual differences. Although we have provided services to this group, our resources have not allowed us to provide all of the services these individuals need. In spite of this, our results are impressive and in some ways shocking.

All are now receiving comprehensive services.

At least three are receiving training in a visual communication system. Two of these each understand over 100 symbols and exceed our technical ability to transmit their expressive capability.

For six individuals, innovative positioning techniques have permitted improved functional abilities and are, hopefully, arresting further postural deformities. This has also allowed four to "see" with their eyes, an experience previously denied because of being locked into a total reflex pattern.

Three were found not to be profoundly mentally retarded. One very young child is deaf with probably normal intelligence. Two older teenagers are certainly in the high trainable range and at least one of them is probably educable.

It is exciting to see a young person, until recently spending most of his time in a crib-type bed and categorized and stigmatized as noncommunicative and profoundly mentally retarded, now sitting up in an adapted wheelchair, learning a means of communicating and, recently, cheering on the basketball team of the University of Alabama as he attended a game.

What was our purpose in working with these 20 individuals? It really was not to work just with the 20 but it was to develop methods which could be used to serve all individuals with the severe handicaps of profound mental retardation and noncommunicative ability. We do not know exactly how many people we are talking about but it is a large number and, of course, the methods used can be used for other people besides these who are so severely involved.

But the development of methods is of no value unless some dissemination is accomplished. Already the techniques developed by the DESEMO project are being applied in Portlow where approximately 1300 individuals reside. They are being used in the State crippled service programs, in public school programs, and in cerebral palsy centers.

Requests for our techniques have been received from many States and from some foreign countries.

I would like to very briefly give you a few specific examples of our work. One is that we have uncovered a very serious question. We have done blood chemical analyses of approximately 700 institutionalized individuals and the question is: Is the high beta carotene level found in the blood an indication of an unidentified inborn error of metabolism and, if so, would then early identification and possible treatment reduce or eliminate some cases of mental retardation or are we dealing with a problem which is the result of the form of food that is so often given to low-functioning individuals?

We have worked to develop a technique of assessing visual acuity in infants and have adapted this technique to the profoundly developmentally disabled. As part of the service, we have done vision function testing of all of the individuals at Partlow State School who are considered to be profoundly retarded. This resulted in the first vision function data on this population.

We have developed a program for instruction in visual symbol communication. The receptive part has been finished and is being used now with a number of people. Those people range from profoundly to mildly retarded, and from profoundly to not at all physically handicapped. Individuals in this program are averaging learning more than one symbol per session and their retention rates range from 90 to 100 percent over a period of a year.

This leads to the problem that is mentioned before and that is that the devices for expression are not generally available within the range of most of the people. They are far too expensive for most of us or they contain very limited data banks. However, the telephone pioneers of the South Central Bell System are working with us at no cost to us now, and we expect to have something that will be easily replicable available very soon.

Simple positioning has been a major problem and, again, the costs range upward from $1,000 and those available have not been very effective. We have now developed a process that will soon be available and the cost will be approximately $50 per person. Our process provides individualized chair insert for an individual.

These are some of the things we have done and are involved in. In general, at our UAP and with our project, we are effectively carrying out the concept of technical assistance as our project members work with people in the field, move in and out of the field as needed, but do not assume the responsibility for the service provision totally ourselves.

In summary, it is my desire to have you and the members of the committee be convinced of the necessity of respectfully designating to certain people the responsibility of providing consultation to service providers, to planning groups, to service delivery systems and to educators. Mechanisms for dissemination of information should be easily accessible and efficient. This is the obvious link between research and development and service delivery and it must be supported if there is to be an improvement in the care of the severely developmentally disabled. UAP's across the Nation are in optimal positions to provide this technical assistance.

I would like to remind the committee that the concept of special project funding is sound and I believe it should continue. DESEMO, although hosted by an UAP, requires special project funds.

Thank you, Mr. Chairman.

Mr. Rogers. Thank you very much.

Mr. Schiefelbusch.

STATEMENT OF RICHARD SCHIEFELBUSCH, Ph. D.

Dr. Schiefelbusch. The particular part of our testimony that I would like to develop relates to what we call applied research. That is a term that could be placed in a number of other categories of terminology. Notice that my colleague just simply referred to it as a program, a program for children.

We sometimes refer to it as research for children or it might simply be called application research in the sense that we take the best that is known in some particular area of work and because of our clinical interest and applications would bring it into the service domain and have the desire and the tenacity to keep working with it until we have developed some new feasibility for the children.

Now, it is this development of new feasibility that interests me the most. I have for over 20 years directed a research institute that has focused primarily on the development of new patterns of training and new environments in which to train children that had previously not been trained.

We began work with the lowest functioning children in our State hospitals. At the time we began, it was not considered feasible to teach them language, to teach many of them to wear clothes, how to play, how to go to the bathroom and how to feed themselves. At times it was almost necessary for us as researchers to take bets with the care personnel of the hospital that it could be done.

I think that history is now almost lost and forgotten, although it was slightly less than 20 years ago that it was demonstrated that you could teach children at the low end of the functioning ladder to do many things that qualified them for different kinds of living and different kinds of environments.

This research I now refer to as a breakthrough in feasibility. It is possible now to contemplate deinstitutionalization and mainstreaming and normalization because there has been a large number of interested people who call themselves researchers in one way or another who got interested in the problems of doing research for the children.

Now, it has not previously been in our legislation for the developmental disabilities that we specifically identified research as such. I think it is clear to us all that we are concerned at the beginning of the developmental disabilities legislation that we train people to do work with children, that we provide the means for improved services and care.

But we did not identify the functioning role of research as such. We had left that to other people. It is, of course, not accidental that a large number of research activities and programs have been carried on but I think we have reached the point now, Mr. Chairman, where we should realize that research for children, if mixed with the other important objectives that we have described, can improve the feasibility of what we are trying to do and literally bring the fruits of our efforts to more children that have previously been denied these service opportunities.

It will also allow us to reach improved patterns of normalization and community living.

It is, of course, a beautiful thing to say that children should have the opportunity to live in the least restricted environment that is feasible for the child. It is good to say that they should live in the mainstream of life but it is not good for a child to live a life in a mainstream that he cannot participate in. We still have far to go in designing programs for training and activities for the children that will allow them to become more able and more capable. That is still in part a job for the applied researcher.

Mr. Rogers. Thank you very much.

Mr. Todd.

STATEMENT OF SHELDON P. TODD, JR.

Mr. Todd. This is really a very important program, the UAF program, and I am honored to be here and I am honored to be associated with my colleagues.

Mr. Rogers. I think the committee agrees with you. It is in the bill.

Mr. Todd. We are delighted it is in the bill. The specific features that are in the bill reflect very much our thinking. We have had an expert task force working a year and one half and every director of the program has gone over the recommendations we have developed.

Mr. **Rogers**. Are there any changes in the bill you think are necessary? Should we write in standards for universities?

Mr. **Todd**. Yes, we are very much in favor of standards for all the programs.

Mr. **Rogers**. Is there anything else?

Mr. **Todd**. We would recommend that the administrative grant be designated as a core grant and a minimum funding level of $250 million per grant——

Mr. **Rogers**. How much, $250,000?

Mr. **Todd**. $250,000, yes, thank you.

Mr. **Rogers**. You frightened me for a minute.

Mr. **Todd**. That is the recommendation.

Mr. **Rogers**. A core grant to each?

Mr. **Todd**. Yes.

Mr. **Rogers**. How is it currently done?

Mr. **Todd**. The mean core grant is $29,000 but there is a wide distribution. The overall program is $68 million and the core grant is basically fund administration and could relate to do that.

Mr. **Rogers**. Are there any other changes?

Mr. **Todd**. No.

Mr. **Rogers**. It is my understanding that research was going on all of the time.

Mr. **Schiefelbusch**. I did not mean that it was not. I meant it had been identified as a specific. You see, it is identified in this legislation in section 121, item 4. It is specifically identified.

I am simply speaking to the fact that we have the technology and the capability now, and it should be built in as a firm part of the program.

Mr. **Rogers**. I agree.

Mr. **Todd**. Mr. Chairman, we are concerned in particular with applying research findings to the actual delivery of services and it is applied research on service delivery.

Mr. **Rogers**. I understand. Thank you for being here. Your presentation and your testimony has been most helpful.

[Testimony resumes on p. 260.]

[Dr. Magarb's, Dr. Moser's, Dr. Bergman's, Dr. Schiefelbusch's, and Mr. Todd's prepared statement follow:]

STATEMENTS OF

PHYLLIS MAGRAB, Ph.D.
University Affiliated Program for Child Development
Georgetown University Medical Center

HUGO W. MOSER, M.D.
John F. Kennedy Institute
Johns Hopkins University

JOAN BERGMAN, Ph.D.
Center for Developmental & Learning Disabilities
University of Alabama

RICHARD SCHIEFELBUSCH, Ph.D.
Bureau of Child Research
University of Kansas

and

SELDON P. TODD, JR.
American Association of University Affiliated
Programs for the Developmentally Disabled

on

H.R. 11764 to amend the Developmental Disabilities Services Construction Act

Respectfully Submitted to The Committee
on Interstate and Foreign Commerce

April 4, 1978

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TESTIMONY

on

UNIVERSITY AFFILIATED PROGRAM

H.R.11764

I. TESTIMONY OF PHYLLIS MAGRAB, Ph.D.

My name is Phyllis R. Magrab. I am Director of the Georgetown University Child Development Center, Associate Professor of Pediatrics, and Chief Pediatric Psychologist at Georgetown University Medical Center. I am currently the President of the American Association of University Affiliated Programs for the Developmentally Disabled.

I, and my fellow panelists are here to speak on the University Affiliated Program (UAP) portion of H.R.11764.

I know that this Committee recognizes:

- persons with developmental disabilities have unique needs

- personnel serving individuals with developmental disabilities must have special training

- Congress created the University Affiliated Program in 1963 as the federal investment in making this training available nationwide.

Today, 46 University Affiliated Programs (UAPs) provide a nationwide network of resources to states and which perform the following functions in an exemplary manner: training, service, technical assistance, and dissemination of research findings. Each of our panelists will stress the activities of the UAPs in one of these areas. Our final panelist will summarize the implications of our remarks for H.R.11764.

It is out of my deep commitment to the developmentally disabled that I am pleased to present testimony. Serving the developmentally disabled is not easy. It is a continual confrontation with our own mortality, vulnerability and inevitably, our own humanity. I recall hearing Jean Vanier, a great french humanitarian speak on normalization and changing concepts in residential care. With poignancy he spoke of working with the developmentally disabled as a revelation of what is mankind; as a response to our own conscience, and our fear of suffering and abandonment. Perhaps it is this depth of philosophic awareness that we all are here today to respond to the proposed legislation.

The University Affiliated Programs make available workers who can provide the diverse and complex services the developmentally disabled need. UAPs have as a major mission the setting of standards of service for the developmentally disabled through exemplary training of professional service workers. UAPs provide interdisciplinary training of professionals and paraprofessionals; exemplary clinical services for developmentally disabled individuals in support of the training mission, clinical research; and technical consultation in assisting service agencies and consumer groups.

Because no single professional has all the skills to solve the multiple problems of the mentally retarded or developmentally disabled, it was the wisdom of the Congress to create interdisciplinary training programs that incorporate the functional areas of health, education, and social services. Over 50 different disciplines actively participate in the UAP training endeavors with a core of over 10 disciplines in most programs. The University Affiliated Programs are unique in their ability to provide training leadership and the application of new knowledge to direct service systems. The UAP program conceived of as a national network provides a viable exchange of optimal training techniques, innovative service programs, and a mechanism for establishing high standards for quality of care. The federal government in partnership with the academic community has over the last 14 years worked towards developing an outstanding manpower base and service delivery system for this special population. It continues to be our joint obligation to maintain UAP programs of sufficient quality to continue to meet the national needs of this group and to continue to maintain standards of excellence through new knowledge and professional training.

Our UAP at Georgetown University places a strong emphasis on prevention and early intervention as a part of its service and training program providing exemplary methodology that is broadly disseminated to the community and the UAP network.

Let me share with you one of my most moving experiences that highlights the importance not only of early and skillful intervention, but also vital need for an interdisciplinary model for training and service. Mrs. G. came to our UAP program when her daughter was approximately 18 months of age, having been told at her daughter's birth that she was a rubella baby with cardiac problems who would be severely retarded. Immediate institutionalization had been recommended. After 18 months of ambivalence, the family came to the UAP as a last resort for advice. The child was neither talking nor walking and had a left-sided paralysis which was a complication of an earlier cardiac catheterization. The interdisciplinary team went to work assessing family status (social work), developmental status (psychology, communicative disorders, physical and occupational therapy), and medical status (pediatrics, neurology). The professionals pooled their information, and then embared on a coordinated treatment program. Initial measures included a hearing aid for the previously undiagnosed hearing deficit, medication for the previously undiagnozed seizure disorder and a twister cable brace for the mobility problem. Language and occupational therapy as well as counseling for the family ensured over a 1-1/2 year period. At the end of that time, based on an interdisciplinary review, the child was found to be functioning in the mildly retarded range, with a broad vocabulary and full mobility. Now at age 7 she is in a public school placement for the hearing impaired, quite independent with much language. Had this child not had the benefit of this type of interdisciplinary programming early in her life, the initial diagnosis of severe retardation and institutionalization would have been a self-fulfilling prophecy.

As a result of the interdisciplinary management of this youngster, her potential to live a productive, happy, relatively independent existence is maximized. Additionally, the family was able to benefit from comprehensive services in one facility as well as an integrated treatment plan. The complexity of this case is representative of many similar cases we see at the Georgetown UAP and points to the need for model interdisciplinary training programs and information dissemination. Through our interdisciplinary management program, future professionals experience an exemplary service program which establishes a standard for the quality of service they provide to handicapped individuals throughout their professional careers.

The need for training is implied by the need for services of individuals and families such as the G's. The complexity of this training is highlighted by the complexity of these needs.

Professionals must be trained in:

Information-exchange:

Techniques and principles of obtaining and transmitting information in a variety of settings to clients, colleagues and others.

Growth and Development:

The application of general principles of human growth and development, both biological and behavioral, and major categories of developmental disabilities.

Community Functions:

Community resources, general problem of delivery of health services, case-finding, and life cycle programming.

Diagnosis and Assessment:

The interaction with developmentally disabled children and their families to assess needs and plan intervention.

Producing Change:

The major strategies of modifying behavior through intervention with clients and families including techniques for producing change in biological and behavioral aspects of clients.

Interdisciplinary Theory:

The major group concepts and processes and their application to interdisciplinary team functioning including major strategies to modify attitudes and to prevent and ameliorate defensive postures which interfere with interdisciplinary functioning; recognition of functions and distinct and overlapping boundaries of various disciplines.

Research:

Use and critical evaluation of appropriate materials in the field of developmental disabilities including techniques of program evaluation and research design.

During the last year, the Georgetown UAP, an average size program, involved over 1400 students through courses, practicums, and traineeship placements: 196 trainees, 497 special training program participants, 274 orientees, 470 students in academic course work. The core course, "Developmental Disabilities: An

Interdisciplinary Approach," was attended by over 70 students. To provide a clinical base for training, some 1,550 patients were served by the Center: 447 by interdisciplinary teams, 758 by special projects, 343 in unidisciplinary programs.

Georgetown UAF, besides training and service, provides, in conjunction with all of its model programs, creative dissemination of information. The infant program for high-risk follow-up and stimulation has in the last year offered two national symposiums, generated numerous applied research articles, and stimulated the development of community replication of our model. Our nursery program for developmentally disabled preschoolers has been a tri-state training arena for headstart and daycare teachers serving as a model for screening and programming. Materials for daycare mothers to provide preliminary developmental screening have been developed as a part of our prevention effort and circulated through the UAF network. Uniquely Georgetown UAF is involved on a regional basis in training juvenile justice workers in identifying developmentally disabled offenders - a public documentary is being developed as a part of the project. These are just a few examples of how our UAF is working towards providing better services and better training of professionals who serve families such as the G's. It is through the combined training efforts of the national network of UAF's that we can provide a broad impact on the quality of care for the developmentally disabled.

II. TESTIMONY OF HUGO W. MOSER, M.D.

My name is Hugo Moser. I am director of the University Affiliated Program at Johns Hopkins University, the John F. Kennedy Institute.

Our program is active in training, service, technical assistance, and applied research. The Kennedy Institute serves the nation, the region, the state of Maryland and the greater Baltimore community. I would like to stress only one area: Services as provided by UAPs, using the Kennedy Institute as an examples.

Handicapped persons in the United States have recently been referred to as "the next minority." Major legislation enacted by Congress -- including the Rehabilitation Acts of 1973 and 1974 and the landmark Education of All Handicapped Children Act -- has assured the handicapped child and his or her family of a rightful opportunity for education, employment and participation in society.

In such a time, it is increasingly important that the young handicapped child be provided with the very best of care, offered by persons who themselves received the very best of training.

This is at the heart of the John F. Kennedy Institute and the University Affiliated Program concept. Working together, the programs of service, training and research combined synergistically to improve the well-being not only of today's child, but of children yet unborn.

As one of the first University Affiliated Facilities constructed under legislation initiated in 1963 (P.L.88-164), the John F. Kennedy Institute has become one of the most comprehensive facilities dedicated to improving patient care for severely and multiply handicapped children and their families.

Affiliated primarily with John Hopkins University and medical institutions, Kennedy is an interdisciplinary facility, fully committed to advances in patient care, training and research. It is licensed and accredited by the Joint Commission on Accreditation of Hospitals.

It is worth noting that we stress the term "interdisciplinary" as opposed to "multidisciplinary". It is our continuing goal to work together with professionals representing various disciplines and in a coordinated effort which has one purpose; better serving handicapped children by viewing them as children with disabilities and not as disabled children. We also stress the concept of continuity of care. Each child with disabilities must be helped as necessary throughout his or her life. It is our belief that service, training, research and technical assistance are, and must be, interrelated. Let me give you an example; in our Kennedy School, we have enrolled a girl whom I shall call Amy. Unlike many handicapped children, Amy was not rejected by her parents. However, as she reached her teenage years her behavior became literally unmanageable, and it was with considerable regret that her parents committed her to Rosewood Training Center -- an institution for the mentally handicapped, where she would spend the rest of her life.

Amy is almost 18 years old, yet she functions as if she were 18 months. She has little self-help skills, and the activities of daily living which all of us take for granted, had to be performed for her by trained personnel. At Rosewood it was likely that she would have lived among equally handicapped, getting no better until she died.

Amy is enrolled in our model program for severely and profoundly handicapped. She has, in less than one year, shown remarkable progress in improving her behavior to the point that her parents feel that she can some day return to their home.

A child like Amy goes through an interdisciplinary evaluation at the Kennedy Institute, in which professionals representing some 15 disciplines would offer their opinions. These evaluations would be combined into a thorough appraisal and recommendations for treatment.

In Amy's case, the first step was to better evaluate her potential and we did so by treating her as a whole child, and not looking just at her deficits. This led to a more realistic assessment of what she could do, including providing her with a program in which she can communicate her wants and needs to others.

By sharing her story in our weekly conferences with trainees, they too are getting a better understanding of developmentally disabled people which they will take with them as leaders in the field elsewhere.

Equally important, we are working closely with Rosewood and with other service providers, offering them technical assistance in how to deal positively with other Amys -- for the goal of this specific program, is to develop a curriculum which can be used nationwide in dealing with children who are so profoundly handicapped or whose behavior is so difficult to work with that they would normally end up on an institutional ward.

Last year, the Kennedy Institute served over 4,400 developmentally disabled children, either as in-patients, or out-patients. These clients included children with Cerebral Palsy, many types of birth defects, Orthopedic problems, seizure disorders, lead poisoning, inborn errors of metabolism, learning disabilities, children who had suffered head trauma, children with behavioral or learning disorders, and children with autism.

In addition, we worked closely with university and residential facilities in Pennsylvania, Maryland, Delaware, Virginia, West Virgina, and the District of Columbia. We focused on the needs of institutionalized persons suffering from seizures or epilepsy, for such persons comprise three out of every ten persons now confined to institutions.

The purpose was to reevaluate the treatment program for all patients with seizure disorder, and develop effective methods of bringing these seizures under control. We are pleased to note that the frequency of seizures did in fact diminish -- and the people suffering from such disorders, showed good progress in terms of social skills, education and vocational training.

It is difficult to imagine separating service from training or training from research. It is only in a milieu that combines these elements, that new knowledge can be unearthed and applied, and then taught to others who will themselves take leadership roles. And the one who benefits most is that handicapped child, who has the same rights that we all do -- a fact we are just now coming to fully realize.

In June of this year we will be conducting a conference on developmental disabilities -- discussing future directions and the challenge of applying what we know. The program will bring together a broad range of disciplines from around the country and will, we hope, be a significant step in sharing our knowledge of service to others equally committed to all handicapped children.

III. TESTIMONY OF DR. JOAN S. BERGMAN

I am Dr. Joan Bergman, Director of the DESEMO Project at the Center for Developmental and Learning Disorders, (CDLD), the University Affiliated Program (UAP) at the University of Alabama in Birmingham, Birmingham, Alabama.

In both in-house and out-reach programs, CDLD provides service to individuals who range in age from newborn through adults. Degrees of involvement of the clients range from mild to profound.

Exemplary service programs at CDLD exist primarily for the purpose of providing a mechanism for the training of students - undergraduate, graduate, and post-graduate - to work with individuals who are developmentally disabled. CDLD faculty and staff provide formal coursework as well as extensive educational experiences in a practicum setting. Both service and training take place within an interdisciplinary model.

Research efforts at CDLD are directed to problems of individuals as well as to problems of service delivery. In addition to documentation and analysis of aspects of service delivery, special laboratories focus on in-born errors of metabolism of an heritable disorder of connective tissue. Other programs operating within the Center provide service and training, as well as research, in human genetics and infections in utero.

The DESEMO Project, Demonstration of Service Modalities for the Non-communicative Developmentally Disabled, is an example of the provision of technical assistance by a special project of a UAP. DESEMO was first established to demonstrate that an interdisciplinary team of mental retardation professionals, parents, supportive personnel and consultants could work together to provide a better quality of life for individuals whose handicapping conditions were of a severity to require total care.

To see what could be done, we selected twenty severely handicapped individuals who, at the time we started working with them, ranged from 7 weeks to 20 years of age. Not one of these individuals was able to communicate either verbally or non-verbally. In other words, none had any way of indicating a desire or need, or indeed of showing understanding of anything. All had been found to be profoundly mentally retarded as measured with standardized instruments. Ten of these lived in the community and ten in a state residential facility. Those living in the community were not receiving comprehensive services. Two had some means of ambulating. Several have severe visual problems and one is deaf. One was tube fed and had no response to any stimulation; one young man has such severe physical deformities that the crest of the pelvis on one side is literally adjacent to the rib cage on the other side, his hands rest on his forearm; the only behaviors exhibited by one is to make rhythmical movements, to make low-pitched sounds and to bite at anything that comes into his reach. Several have spent their lives in cribs or crib-like wheeled objects. Unfortunately, these twenty are representative of individuals who are found on back wards of institutions and for whom the care routinely given recognizes in them no human potential. There is little positive that could be said regarding the quality of life for either these individuals or their parents.

The 20 were deliberately chosen with a wide range of individual differences. Although we have provided services to this group, our resources have not allowed us to provide all of the services these individuals need. In spite of this, our results are impressive and in some ways shocking.

- All are now receiving comprehensive services.
- At least three are receiving training in a visual communication system; two of these each understand over 100 words and exceed our technical ability to transmit their expressive capability.
- For six individuals, innovative positioning techniques have permitted improved functional abilities and are, hopefully, arresting further postural deformities. This has also allowed four to "see" with their eyes - an experience previously denied because of being locked into a total reflex pattern.
- Three were found not to be profoundly mentally retarded. One very young child is deaf with probably normal intelligence. Two older teenagers are certainly in the high trainable range and at least one of them is probably educable.

It is exciting to see a young person, until recently, spending most of his time in a crib-type bed and categorized and stigmatized as non-communicative and profoundly mentally retarded, now sitting up in an adapted wheelchair, learning a means of communicating and, recently, cheering on the basketball team of the University of Alabama as he attended a game.

It is exciting to hear that for the first time, specific children attending a classroom for the profoundly retarded are able to make their needs known to their teachers and parents and are even "talking with each other."

What was our purpose in working with these 20 individuals? We worked with these 20 individuals to develop methods which can be used to serve all individuals with the severe handicaps of profound mental retardation and no communicative ability. No one knows for sure how large this group is; one estimate places it at 300,000 individuals in the U.S. Of course, this group is very severely handicapped; however, many of the methods described can be and are being used with individuals with other handicaps.

Already, techniques developed by the DESEMO Project are being applied in Partlow (where approximately 1,300 individuals reside), in a State Crippled Children's Service program, in a public school system, and in a cerebral palsy center. Requests for our techniques have been received from many states and some foreign countries.

Some specific examples of our work include:

- identification of the developmental milestones in vision;
- development of a technique of assessing visual acuity in infants and the adaptation of this technique to the profoundly developmentally disabled;
- vision function testing of the individuals (approximately 600) residing at Partlow State School categorized as profoundly retarded -- this resulted in care for individuals as well as the first vision function data on this population;
- major input into nutritional care at a state facility where approximately 1,300 individuals reside;
- blood chemical analyses of approximately 700 individuals leading to a critical and, as yet, unanswered question. Is the high beta carotene level in the blood an indication of an unidentified in-born error of metabolism and, if so, would early identification and treatment reduce or eliminate some cases of mental retardation or is the problem a result of the form of food given to low functioning individuals?
- development of a program for instruction in visual symbol communication. Blissymbolics is the system

we have chosen to teach. The receptive part of the program has been developed and has been used with a population ranging from profoundly to mildly mentally retarded and from profoundly to not physically handicapped. Individuals have averaged learning 1.12 symbols per session (average length of time, 20 minutes) and have retention rates of from 90 to 100% over a period of a year. The program is now in use in several centers. The protocol is being published in order to make the program available to others. People from all over the U.S. and from several foreign countries have requested copies.

The device to use for expression has been a major problem with those available commercially having very limited data banks and/or having costs ranging upwards from several hundred dollars. The Telephone Pioneers of the South Central Bell Telephone System are joining with us, at no cost to us, to solve this problem. We expect an inexpensive, easily replicable device to be developed shortly.

- Simple positioning is a major problem for people in our target population. Not only can they not support themselves in a sitting position, but most have such severe physical deformities that they cannot be propped in a purposeful way. Devices available cost upward of $1,000 and are generally unsatisfactory. We have developed a process for making an individualized chair insert, molded to the individual's body -- whatever the configuration. This is now in the field trial stage. We anticipate the cost to the consumer to be no more than $50 per insert.

These are only some of the things we have done and are involved in. In general, at our UAP and with our Project, we are effectively carrying out the concept of technical assistance as our Project members work with people in the field in identifying and then intervening with problems, but always working with a local care-giver, not assuming themselves responsibility for the daily provision of service.

Summary. It is my desire that you be convinced of the necessity of specifically designating to certain people the responsibility of providing consultation to service providers, planning groups, service delivery systems, and educators. Mechanisms for dissemination of information should be easily accessible and efficient. This is generally called technical assistance and is the obvious link between research and development and service delivery, and must be supported if there is to be an improvement in the care of the severely developmentally disabled. UAPs across the nation are in optimal positions to provide technical assistance.

Special project funding is sound and should continue. DESEMO, though hosted by a UAP, required special project funds.

IV. TESTIMONY OF RICHARD SCHIEFELBUSCH, Ph.D.

My name is Richard Schiefelbusch. I am Director of the Bureau of Child Research at the University of Kansas.

The importance of applied research in the program of the University Affiliated Programs (UAP's) has increase significantly since the program was begun in the middle 60's. At the beginning, it seemed certain that we needed significantly more trained professional personnel to serve the large numbers of neglected and poorly cared for handicapped people. Also, we assumed, correctly I think, that the training ceuld best be provided in university sponsored interdisciplinary centers where trainees could observe the best programs of service and service instruction available. In this manner we hope to improve the quality of personnel and the quality of programs for the handicapped and the developmentally disabled into various service settings in institutions, schools and the communities.

The functions underlying the plan was that the professional expertize already existed for providing the service and the training and if not it would come from the normal infusion of information from basic and applied research sponsored by the settings in which the UACs were located. Presumably the relevant research was to be sponsored by funds from federal, state and private sources not directly responsible for the programs of the UAPs.

During the years since 1963 a number of important changes have taken place in the UAPs and the priorities they serve. It is now apparent that the UAPs should sponsor applied research projects that bear directly on the training and on the exemplary service mission that they have undertaken. Furthermore the research mission of the UAPs may now be viewed with the same sense of importance that is given to training and service.

Urgency stems from the revolution that is taking place in the pattern of services and indeed in the way of life that society has decreed for the developmentally disabled. They are now being deinstitutionalized and mainstreamed. They are now being moved into the educational, recreational and social systems of communities. As this takes place and as we prepare for normalization we find shortages in our training programs and in our models for environmental designs and in our programs for daily living.

There is a vast number of potential problems surrounding the effort to give the handicapped equal rights to a life of dignity and fulfillment. Our purpose in the very brief time available is to sketch a few of the most important issues which should now be researched. First, we need research on existing service systems for the developmentally disabled. Several questions have arisen; are current service programs appropriately designed in regard to costs, educational, rehabilitative gains and health care provisions? As we change from institutional to community based services, are we selecting the best models for the new programs? Best should be considered to be those programs which offer the most effective arrangements for the lowest unit costs.

Research of service systems is especially important for the severely disabled. If they are to live successfully in least restrictive environments there must be suitable living arrangements, training programs and care provisions. The design for these efforts should be worked out by service providers with participation of UAC personnel who have the necessary expertise for designing and implementing service plans. The best developments of such efforts will often require applied research.

In addition to research on service delivery systems we also need research on care programs. Many communities are not likely to have the medical personnel to plan for and to service the severely handicapped. Consequently, we need research leading to special designs for technical assistance and for in-service training. A close relationship must be established in which UAP personnel visit communities and help to design plans for new services. Epidemiological data cost estimates and sources of support must be matched up with needs estimates. Beyond this planning there must be a monitoring system that serves much the same purpose that a clinical service department provides in a resident setting or a teaching hospital.

These two examples, service delivery, and care programs, are only two of many applied research areas that should be developed or expanded.

The applied research we recommend is essentially of two kinds, (1) the applications of basic research findings and research methods to the problems of the developmentally disabled, and (2) research that is designed to solve some important problems of the developmentally disabled population. We are aware that many important developments in health care, rehabilitation, education and community living have come from the applications of basic research to the problems of the handicapped. The critical application came about because some alert professional worker knew about the basic work, understood its potential and was creative in applying the method or the procedure for children in settings far different from the one in which the research was performed. Thus, the work of Piaget on cognition, Sidman on perceputal generalization, Osgood on language models or Premack on primate language had been adapted to serve the learning objectives with severely delayed children. One must understand however, that these applications were not easily developed. The special individual differences and individual needs of developmentally disabled children must be carefully considered before the most ingenious research findings can be applied. Careful plans and careful assessments must be undertaken and the results must be carefully considered in refining procedures. Finally, the approach or the method in question must be described in great detail so that others can be taught to perform the procedures in order to get similar results. Otherwise the desirable effects of the bold new procedures are not likely to generalize to the many settings where developmentally disabled children live.

The careful work just described has led to the creation of a technology for applied research that we did not have a few years ago. We can now undertake to improve services that we previously developed by guesswork or tradition. The combining of epidemiological data designs with systems planning for instance, enables the planner to estimate more closely the service needs and the cost figures for a community. The transdisciplinary efforts of professional teams from the UACs are now able to train service staffs and to follow through in providing a balances and often lower cost service staff for the community setting.

It may seem tedious for me to point out the general mechanisms for applied research with the developmentally disabled. However, we should realize that it was the careful, tedious applications of applied researchers of 10, 15 and 20 years ago that have given us the credibility we enjoy today. In factthe breakthroughs in feasibility that they have achieved now enable us to teach the severely retarded and to consider placing them in community settings and to include them in classrooms ahd work activity settings. It was these applied researchers who looked for better methods for the handicapped and who did not stop until they found a better way, that we are seeking to increase in number and to place in more prominence in future planning for the handicapped.

V. TESTIMONY OF SELDON TODD

My name is Seldon Todd. I am Executive Director of the American Association of University Affiliated Programs (UAPs) for the Developmentally Disabled. The Association represents 46 University Affiliated Programs funded by the federal government. The Association supports H.R.11764 in general and the UAP portion specifically.

The proposed language would:for UAPs:

(1) Legislatively update a sound program initiated 15 years ago.

(2) Solve some important problems in the implementation of the program.

(3) Extend the program in a modest but significant way.

Definition of University Affiliated Programs (UAP)

We support the definition of university affiliated programs as presented in Sec. 3 of H.R. 11764, which would amend Paragraph (10) of Section 102.

At present, University Affiliated Programs (UAP) are legislatively defined and provided administrative support under this Act but are also funded under several other authorities. The lack of a specific comprehensive definition of UAP has interfered with the Secretary's ability to coordinate the different funding elements of the program. It is the intent of Congress that UAPs provide a nationwide network of resources on which states can reliably count to perform certain specified functions in relation to the systems which deliver services to developmentally disabled individuals. The definition of UAPs specifies that each and every program conduct portions of the following functions in an exemplary manner: training, service, technical assistance and consulting and dissemination of research findings.

The definition presented in H.R. 11764 is compatible with the recommendations of a group of national leaders who formed a Long-Range Planning Task Force on University Affiliated Facilities and issued a report entitled The Role of Higher Education in Mental Retardation and Other Developmental Disabilities in October 1976. They recommended that the UAPs, a significant national resource created by Congress, extend its mission in three areas:

- First, technical assistance should be systematically offered to state and local agencies.
- Second, UAPs can and should help bring new service methods to individuals with developmental disabilities. There have been significant "breakthroughs" in research which could, if applied, substantially reduce the number and degree of developmental disabilities. This directly fits the training and demonstration service roles.
- Third, UAPs would also be required to identify areas in which services could be improved through service related research and bring such areas to the attention of government and other agencies sponsoring such research. Service related research,

generally ignored to date, would greatly increase the effectiveness and efficiency of services.

The definition also proposes that University Affiliated Facilities be changed to University Affiliated Programs. When the program was initiated in 1963, there was a serious need for construction. The situation has changed today, with Universities able to rent or assign space to the new programs. For example, the UAP program at the University of Michigan, one of the nation's first UAPs, occupies a large leased building.

Administrative or Core Grants

Sec. 121(a) presents a better statement of the purpose of the basic UAP grant authority than current law. Specifically, "core funds" are needed to administer and operate each UAP.

UAPs are now funded by multiple sources. The Grant Authority under this Act will continue to furnish administrative support to the program but further require the Secretary to establish standards that all UAPs must meet as a condition of recieving funds as UAPs. We recommend that Congress specify $250,000 as a minimum core grant level. By doing so, Congress would be making its intent that each UAP be examplary. In the past, funds made available through the appropriations process have been spread too thinly across programs, thus compromising program quality. The $250,000 figure was recommended by an independent panel of experts: The Role of Higher Education in Mental Retardation and Other Developmental Disabilities, 1976.

It is also recommended that the word "core" be inserted in the legislation to strengthen the understanding by HEW that funds made available under this Act are for administrative purposes and must be tied together with programmatic support from universities, states, and other federal authorities.

Applications (Sec. 122)

The language of H.R. 11764 would effectively solve several important problems now faced by the UAP program.

The requirement that the Secretary establish standards for UAPs would help insure that every UAP funded under this Act is of a quality adequate to carry out the missions specified by the definition of UAPs. In the past, HEW has in some instances, spread funds too thin.

For those programs which do not meet standards once established, a three year time-phased capacity building period will help insure that all states with existing programs will continue to be served.

The establishment of a formal application process requiring review by each Federal agency providing funds to the UAP program will enhance program coordination and effectiveness. At present, the Developmental Disabilities Office, the Office of Maternal and Child Health and the Bureau of Education for the Handicapped each provide UAP funds. No formal requirement for coordination of the expenditure of these funds exists within HEW, although coordination was clearly intended by Congress when the program was first created in 1963.

The creation of a formal HEW coordinated application process will also establish orderly, nationally understood and consistent application procedures for the creation of new UAPs. In the past, procedures for establishment of new programs have at best been haphazard.

Grant Authority - Subsection 121(b)

Section 121(b) authorizes cooperative applications from state government agencies and UAPs in the following four areas of national priority. A modest time limited investment in these areas will promote nationwide progress through competition and example.

1. Provision of Services to Individuals in Remote Geographical Areas

Sec. 121(b)(1) will continue a nationally funded portion of the satellite center concept contained in P.L. 94-103. However, it is intended that major responsibility for the satellite program be transferred to the state level in the standards to be established by the Secretary. Such standards shall require each UAP as a part of its basic mission and funding to work with appropriate state and local agencies to create service capacity in geographical areas which are now unserved or underserved. Needs in unserved areas can be more effectively identified and met at state and local levels than at the federal level. However, some areas, such as Indian reservations, can not be fully and effectively treated by states alone. Hence, some funds are authorized for expenditures at the federal level.

2 and 3. State Manpower Planning/Training of Service Providers

Sections 121(b)(2) and (3) are intended to stimulate the development of better methods and working relationships between state agencies and UAPs on the planning and training of personnel that provide service to developmentally disabled individuals. Most service personnel are paid in whole or in part by state funds. At present, UAPs concentrate mainly on training of professionals prior to their entry into the service system and state plans have tended to ignore manpower planning. Since almost all services to developmentally disabled individuals are "personnel" services and the effectiveness of such services are often highly sensitive to the quality of such services (e.g., diagnosis and treatment planning, custodial vs. developmental services), this lack represents a significant gap in existing state "planning-service" systems.

These provision will help UAPs support the development of State Plans under Sec. 11(b)(6) of H.R. 11764.

H.R. 11764 [Sec. 11(b)(6)] requires that each State Plan provide for "an assessment of the adequacy of the skill level of professionals and paraprofessionals serving persons with developmental disabilities in the State and the adequacy of the

State programs supporting training." This is a highly important feature of H.R. 11764 and may prove to be one of the most far-reaching provisions of this bill.

4. Service Related Research Program

Section 121(b)(4) is intended to fill another major gap - research on improving service effectiveness, as discussed by Dr. Schiefelbusch. Federal funds now sponsor basic MR research and support training. Very little work has been sponsored to improve methods of delivering proven services. A modest investment of federal funds offers the promise of saving many times the amount of investment since services are highly labor intensive, often expensive (e.g., interdisciplinary diagnosis), and often dependent on quality for effectiveness.

Special Project Grants

This authority has been very important to individuals with developmental disabilities and should be continued in H.R. 11764. It is important because special project grants have supplied funds for sorely needed demonstration programs related to the delivery of services to developmentally disabled individuals or to training of manpower to support such services.

An example of cooperative effort in the study of the aging process of developmentally disabled persons is the federally funded Project of National Significance which brings together five UAPs in a consortium formed specifically for this project. Each UAP is examining an area of concern in serving the aging and aged developmentally disabled population. Results of this consortium project will be disseminated nationwide and should have impact on our knowledge of the aging process and our ability to manage it in the developmentally disabled person.

Mr. ROGERS. Our last panel today is an additional advocacy group, Mr. Richard Verville, Legal Counsel for the National Easter Seal Society for Crippled Children and Adults; Ms. Margaret Caulfield who is Coordinator of the Osteogenesis Imperfecta, National Capital Area; and Mrs. Linda G. Connors who is a Representative of the Tuberous Sclerosis Association of America.

We welcome each of you to the committee. Your statements will be made a part of the record in full. You may proceed.

STATEMENTS OF RICHARD E. VERVILLE, COUNSEL, NATIONAL EASTER SEAL SOCIETY FOR CRIPPLED CHILDREN AND ADULTS; MARGARET CAUFFIELD, COORDINATOR, OSTEOGENESIS IMPERFECTA, NATIONAL CAPITAL AREA; AND LINDA G. CONNORS, CODIRECTOR, TUBEROS SCLEROSIS ASSOCIATION OF AMERICA

Mr. VERVILLE. Thank you, Mr. Chairman. I am appearing in behalf of the Easter Seal Society as you have indicated.

Mr. ROGERS. Your statement will be made part of the record in full [see p. 263.]

Mr. VERVILLE. I will highlight it. There is not much that one can add to what you have so thoughtfully listened to for the many hours. I was particularly touched by Mary Akerley's statement which dealt with a somewhat different strain, which is a moral one, that you do not necessarily hear often in these committee sessions. But I think it is not only poignant but appropriate here.

The only thing I would like to mention is that the issue that this bill generates is that there is not a system of dealing with chronic disability in this country. We have paid a lot of attention to acute care and your committee, which I have watched over the last 8 years at least, has done some remarkable things with regard to the Health Maintenance Organizations, the Planning Act and I think over time these are making changes in the acute system.

But I think people with chronic disabilities that are as severe as the disabilities you are hearing from today present particularly troublesome problems. These are people who obviously have a chronic disability which means it lasts over a long period of time.

The severity results in the fact that they need services from a variety of institutions and service providers that come from different perspectives when you are down at the local level and even for the providers, who are trying to take care of them. I think it is difficult to deal with.

I think a number of people have talked to that today. Mark Akerley spoke to that; for the person involved, it will be more difficult because they are suffering from that disability which has generated all of these issues. I certainly think that through your jurisdiction over matters like health insurance, the Planning Act, improvements in medicaid, some real changes can be made that will help this population.

I think this act, the DD Act, is important, at least at this period in time, because it is probably about the only mechanism for attempting to organize care and do some planning to improve the situation that I have described.

That leads me into the definition because I think you cannot, as my statement indicates, answer this question of what the definition should be through semantics or through science. It is just a question of what definition works best, given the purposes of the law and the purposes are those that I think I have attempted to lay out.

To me, this means you have to start with a definition that is functional, that tries to define that category of people that are so, to use an inartistic phrase that Elizabeth Boggs has used, so severely clobbered that they really cannot, even with the help of caring family, manipulate that system very well to organize the services they need.

I think it makes sense to limit the definition to disabilities that are manifested at an early age because I think with regard to those disabilities, there is a particular impediment to one's maturation and development that leaves these people particularly vulnerable.

Mr. ROGERS. Do I understand you support the majority position on the Commission?

Mr. VERVILLE. More than the minority and more than the present law. I was on the task force and I must admit some people accused me of taking a walk in the last meeting. I did not vote. I was not there. Had I been there I would have voted for the majority opinion because I was given just two options.

The only problems I have with the majority opinion are that I think the last two elements are rather vague and it is hard to figure out what the intent is and they will be very hard to administer. I think some language dealing more precisely with the notion that the impairment limits their knowledge and their skill in such a way that they are unable to function in the ordinary social setting such as employment or planning one's own affairs would be a much clearer way to state those.

I do not think you need the last one, to tell you the truth. I think the minority report is very misleading. I think some people feel it makes a major change and I do not think it really does at all. I am sure that the drafters of it believed it would have such a limited effect as I do.

But I think it would have no effect. I think just the addition of those four categories to mental retardation in the so-called similarity test will have little or no effect in operation. There is a similarity test in the law now, "similar to mental retardation." To my knowledge, there has been very little expansion of the program.

The three things you are adding are supposed to be similar to mental retardation. If they are similar to mental retardation and nothing else has been found similar to retardation, it is doubtful you will find anything similar to those four to deal with just the logic of it.

I think you need a functional test. I think the report language in the bill can be and probably should be very specific about the types of disabilities that the committee is thinking about. I think those disabilities clearly include the four that are named in the law and I think some others probably should be included.

I would like to submit for the record a few examples of cases that the rehabilitation centers have had which kind of graphically show you, because they are supposed to be samples of cases of children—there are two CPs, three spina bifida, one spastic hemiplegia, and the services the people need are basically all the same.

Mr. **Rogers.** Without objection it will be made part of the record.

Mr. **Verville.** Thank you, Mr. Chairman.

[Testimony resumes on p. 264.]

[Mr. Verville's prepared statement and attachments follow:]

STATEMENT OF

THE NATIONAL EASTER SEAL SOCIETY FOR CRIPPLED CHILDREN & ADULTS

Before The

HOUSE SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT

Of The

INTERSTATE & FOREIGN COMMERCE COMMITTEE

ON H.R. 11764

April 4, 1978

Mr. Chairman:

I am Richard E. Verville, Legal Counsel and Consultant to the National Easter Seal Society for Crippled Children and Adults. I served on the National Task Force on the Definition of Developmental Disabilities and chaired the Committee dealing with the relationship of the developmentally disabled population to other Federal programs. I also serve as Secretary-Treasurer of the Coalition for Health Funding, and Vice Chairperson of the ABA Committee on Health, Education & Welfare Law. I am testifying today on behalf of the National Easter Seal Society for Crippled Children & Adults ("Easter Seal"). We welcome these hearings and express our gratitude to you for your continuing interest in the Developmental Disabilities Act and other programs for the disabled. This Subcommittee has shown support for and interest in the health needs of chronically ill and disabled people through incorporation of medical rehabilitation services in a number of comprehensive health care programs.

The National Easter Seal Society for Crippled Children & Adults, a major voluntary agency organized 58 years ago, provides physical restoration and other rehabilitation services for physically disabled persons including those with "developmental disabilities". Annually, approximately 360,000 disabled persons receive direct services from affiliated societies which operate 2,000 programs and facilities including 300 comprehensive medical rehabilitation centers and numerous workshops and special education programs. In 1975, $51.5 million of the $68.7 million expended was for program services. The 300 outpatient rehabilitation centers are major providers under health financing programs.

I. Care and Services for Severely Disabled and Chronically Ill

Like many other issues which arise with respect to health care, services to the chronically ill and disabled are most notable for their lack of organization and management. However, these problems for this population are particularly acute because of the growing size of this population, the duration of care needed, and most significant, the diversity of care and services needed. It has been estimated that 80% of all illness in this country is chronic. "Learning to be Your Own Doctor", Sandra Rosenzweig, New York Times Magazine, April 3, 1978. HEW estimates that about 14% of the noninstitutionalized population, or 30 million people, suffer from functional limitations resulting from chronic disease. "Health, United States, 1976-1977" HEW-PHS, Publication 77-1232, p. viii. This population, however, accounts for 41% of hospital days and 27% of physician visits. Supra. In addition, a recent Urban Institute Study found that about 93% of the 2 million individuals institutionalized in nursing homes, mental hospitals, mental retardation facilities and chronic disease hospitals were severely disabled. "Comprehensive Service Needs Study" June 23, 1975 (HEW 100-74-0309) ("CNS"). The "Comprehensive Service Needs Study" estimates that about 6 million individuals have severe disability resulting from chronic illness or accidents. This Study indicates that for the population 18-64 with severe disabilities, the impairments are generally orthpedic or musculo-skeletal (25%), neurological and mental (18%), or cardiovascular (25%). CNS, page 80. Typical cases include mental retardation, cerebral palsy, convulsive disorders, arthritis, multiple sclerosis, muscular dystrophy, visual impairments, spinal cord injury or disease, stroke, diabetes and its complications. See CNS, page 69-88.

To provide more immediate and living examples of these statistics, we recently requested a representative group of our rehabilitation centers to provide sample case profiles of those served. We would be happy to provide such profiles for the record. The typical cases are young children with cerebral palsy, spina bifida, spastic hemiplegia, deafness, and adults with stroke.

How do our existing health and social agencies and professionals care for this population? The needs of this population vary enormously depending on the type of disability, but commonly most all severe disabilities (those leaving individuals with serious limitations preventing them from carrying out typical activities of living) demand services at some time during their chronic condition from all major elements of our health and social service systems: health care, including acute and rehabilitative (inpatient and outpatient); special assistance with regard to daily living and residential needs; social services such as recreation, training to care for oneself; transportation assistance, education; vocational training and placement. See CNS, pages 144 and 189 reflecting a survey of 900 severely disabled individuals determined by state rehabilitation agencies to have no immediate vocational goals or served in comprehensive rehabilitation hospitals.

Generally, these cases will all have some degree of need for health services. The current health agencies are limited in their ability to meet even the health needs. For those with physical disabilities there are inpatient rehabilitation programs in rehabilitation hospitals (50), or rehabilitation units of general hospitals (380). In addition, there are about 210 outpatient rehabilitation centers accredited by the Commission on Accreditation of Rehabilitation Facilities and another estimated 300 which could achieve that status, some of which are Joint Commission on Accreditation of Hospitals ("JCAH") accredited. The comprehensive programs among these seek to manage care over the duration of disability including vocational adjustment, social services and continuing primary and rehabilitative health care. However, there are obviously very few of these comprehensive programs: perhaps about 400 as estimated by the Commission on Accreditation of Rehabilitation Facilities ("CARF"), or 8 per state. And it must be remembered that these programs only deal with physical disability, not mental retardation and not all neurological impairments. Also, even where these programs do exist, there is no systematic way of assuring management of care for the chronically ill who may move from a physician to a nursing home or a general hospital to a nursing home.

At various times proposals have surfaced to deal with the lack of programs to manage on a continuous basis the care of chronically ill and disabled people. Community Long-Term Care Centers have been proposed as a part of health insurance financing, and Senator Humphrey had proposed chronic care centers. Yet, the attention of health planners and policy-makers has been fixed primarily upon acute care problems and the need for improved systems to manage and prevent illness, e.g., HMOs. While the Health Planning & Resource Development

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Act is focused on improving the methods of delivering care, it likewise, has not and probably will not focus on chronic care and the integration of health, social and other services.

II. The Developmental Disabilitites Act -- a Definitional Problem

How does this prior analysis relate to the current issues regarding the Developmental Disabilitites Act? First, the definition of Developmental Disabilities ("DD") cannot be developed independent of the structure and purpose of the program. Neither medical science nor semantics will produce an answer which lawmakers should use. The most appropriate definition will be one which best serves the goals of the program. Second, the goals of the program have been (and are even more clearly so in H.R. 11764), to plan for and organize needed health and social services for the DD population. Essentially, the program has always been intended to focus on those severely disabled people with chronic impairments substantially limiting their "ability to function normally in society" and for whom such programs are of critical importance because they are often left out of the "system". It has, however, in effect been limited to four categories of severe disability: mental retardation, cerebral palsy, epilepsy and autism. These clearly are diseases which can and often do result in severe disability affecting one's capacity to perform ordinary social functions like work, management of a household and one's own basic living needs such as mobility, communication, etc.

Our societies presently serve many DD persons, mainly those with cerebral palsy. However, we do not believe that definition should be by disease as it is now, but rather by a functional description of disability. As a result, we do not support continuing the present definition. Nor can we support the ABT Report minority opinion because, regardless of the motivation of the minority opinion, it simply restates the present law in effect. The only difference between present law and the minority report is the inclusion of cerebral palsy, epilepsy and autism with mental retardation as diseases which, if a disability is similar to them in effect and services needed, it too is a developmental disability. Under present law, the "similarity test" is exactly the same but the similarity is only to mental retardation. That approach has not resulted in a broadening of the program. There is no proof that other severe disabilities are more likely to be similar to the other three since all four are basically conceived of as being similar to each other. Also, it is terribly difficult to determine when one disability is similar to another and particularly when each disease has a broad range of different populations within it. If the test were just the functional one of an impairment of "intellectual functioning and adaptive behavior" suggested in the minority report, and if adaptive behavior meant ability to adapt to major social requirments such as work or independent living ability, the minority report would be reasonable. But it is not so structured. The definition is really the present law. In addition, adaptive behavior is a very vague concept as written.

We also have some difficulty with the majority recommendation of the Report despite its functional focus. It has a number of elements which are vague and which would be difficult to administer. It seems needless and confusing to set forth a laundry list of six types of functional limits of which three must be met. First, some of the six are very vague and two of the six are similar: self-care and independent living. Second, three (mobility, language, learning) seem to be apples and the others oranges. Finally, there seems to be no need for the last very general and unclear element: the need for a sequence(?) of special, interdisciplinary or generic(?), services of extended duration and individually planned and coordinated. All of these words are not good for a definition which must be used by administrators of programs. They are probably unnecessary because the remainder of the definition clearly implies that substantial services are needed over a long period. If any element is necessary along these lines, it should be the requirement that "services are needed from diverse elements of the health, education and social service systems".

We would agree with the requirement that the disability be chronic and be manifest early in life (22 may be as good a cut-off as any, but it could be earlier). We would suggest, however, that the disability be "any impairment resulting in substantially limited ability to acquire the skills and knowledge necessary to function normally or adapt to normal social requirements such as work or the independent management of daily living activity". If this is the use of the term "adaptive behavior" meant by the minority report and if the limiting and somewhat arbitrary requirements of similarity to one of four diseases were eliminated, our approach and the minority are not far apart. Our definition is very similar to the majority definition, but more precise and clearer, we believe.

It must be remembered that we are not creating provisions of a social insurance system where the categories of eligibility need to be very narrowly drawn. Some flexibility should be allowed to state councils and agencies to target on the neediest of these vulnerable groups. While targetting of limited resources can be argued as a basis for categorizing the definition as under present law, the targetting clearly can be done at the state and local level.

III. Conclusion

The Developmental Disabilities Act is a response to the lack of programs to manage care for severely disabled people needing many health, social and educational services over a lifetime. Because of their severe disabilities and because of their many and diverse needs, they are often without a program to assure that their health and social needs are met. Many become institutionalized. Yet, a reasonable estimate is that there are about six million individuals in this status. While major reform of health financing and programs to focus on organizing to meet the needs of these populations would be more than welcome, H.R. 11764 is an important, though limited step to assuring better care for these populations. We think the substantive changes in H.R. 11764 are sensible and are likely to improve the program. We think the program should focus on those individuals who meet a functional test, however, rather than those who must establish similarity to a disease as under current law. Our suggested definition has been discussed and is attached.

Thank you for this opportunity to testify regarding the needs of severely handicapped people. We urge you to keep their needs constantly in mind as you carry out your enormous responsibilities of overseeing and legislating the nation's major health programs: Medicaid, health insurance, health planning, and health manpower.

ATTACHMENT A

NATIONAL EASTER SEAL SOCIETY FOR CRIPPLED CHILDREN & ADULTS DEFINITION APPROVED IN 1973:

> "A developmentally disabled person is one with a physical or mental condition, originating before age 18 which is not responsive to treatment, which therefore can be expected to exist during the life of the individual, and which leads (or has led) to functional deficits which substantially interfere with the individual's ability to acquire normal skills and knowledge, to engage in competitive employment, or to manage his own affairs without assistance".

October 4, 1977

[redacted]

From: Wm. Spencer, M.D.
R. Verville, LLB.

HEALTH CARE AND THE DISABLED OR CHRONICALLY ILL

A. General

The disabled have traditionally not had adequate access to health care in this country. Private insurance may exclude them because of pre-existing conditions or not have coverage adequate for the catastrophic expenses often involved. Medicare includes the disabled eligible for Disability Insurance, but requires a 29 month waiting period. Both private insurance and Medicare do not cover some of those health programs most needed by the disabled: medical rehabilitation and home care. Medicaid picks up the disabled who spend down into poverty, but inpatient care is limited to about 20-30 days and outpatient care is very limited. This paper explores these health care programs for the disabled -- medical rehabilitation and home care -- in some depth in order to adequately define them and to justify their inclusion, as well as coverage for the disabled in a national health insurance program.

B. Medical Rehabilitation Programs and Their Difference From Nursing Home Care, Home Health, or Other Forms of Long-Term Care.

Medical rehabilitation is a medical process which involves a multidisciplinary team approach to care and a broad range of services for a defined group of individuals having or facing disability. The care is a total program for the patient. A physician is always involved and directs a plan of care established by the rehabilitation team. The team and the services it provides include the participation of a rehabilitation physician, a rehabilitation nurse, physical therapists, occupational therapists, medical social workers, audiologists and speech pathologists, psychologists, and other professional technical persons including vocational counselors, educators, etc. In addition to these services, other parts of the program include the fitting and provision of braces, orthotic devices, or prosthetic devices (artificial limbs) and the usage of special assistive equipment for daily living. The plan of care is a written one and establishes specific goals related to expected functional improvement in performance of daily living activity. Medical rehabilitation may assist the disabled or potentially disabled person of any age (children, adolescents, working age adults, and the elderly). Medical rehabilitation takes place in both an inpatient setting in a hospital (either a specialized rehabilitation hospital or, less often, in a rehabilitation bed unit in a general hospital), or in an outpatient setting in an outpatient department of a hospital or a rehabilitation facility which provides only outpatient services and is not part of a hospital though accredited as a rehabilitation facility. An example of the latter would be a free-standing rehabilitation facility sponsored by the National Easter Seal Society for Crippled Children & Adults. There are eight such centers in the State of Connecticut alone, and they form a network of comprehensive rehabilitation care on an ambulatory basis.

In an inpatient setting, rehabilitation is an intensive type of program analogous to other forms of specialized intensive care such as kidney dialysis units, cardiac care units, etc. It is intensive because of the extensive and continuous physician involvement and the active program of services provided by rehabilitation nurses, physical and occupational therapists, speech pathologists and audiologists, medical social workers and psychologists under the direction of a physician.

Outpatient rehabilitation takes place in a hospital outpatient department or a facility which is not a hospital but is licensed to provide outpatient rehabilitation services and is generally accredited by the Commission on the Accreditation of Rehabilitation Facilities. The services are not isolated or discrete as would be the common case in a follow-up clinic visit for a special medical evaluation or a speech therapy service, for example. Rather, a physician knowledgeable in rehabilitation directs the program and it is multi-service in character including physical and occupational therapy, speech pathology and audiology, medical social work and psychological services. The program is less intensive than for those requiring inpatient care, because there is need for less continuous physician involvement during any 24 hour period and fewer service hours per day. Yet, the program is goal-oriented and intended to achieve active and major changes and gains in the patient with regard to function and performance in daily living. It generally offers a range of services that are at a much higher level of care and more active than found in nursing home care or home health visits. This activity is far from the level and intensity of care provided to the resident in an extended care facility, a nursing home, or an intermediate care facility ("ICF"), or even a chronic disease hospital. In these latter settings, a physician is not continuously involved in the case and supervising and managing the care program and the services provided are generally only single components of the above or include no rehabilitation care at all. There is some utilization of general nursing and physical therapy services for particular care needs in most skilled nursing facilities, but there is not an active individualized and integrated program in nursing homes or ICFs.

As the study cited on page 6 of the attached testimony, Document A, shows, inpatient hospital care will generally improve functional ability very substantially from 35% of normal at admission, to 75% at discharge.. Nursing home or related care is generally used to maintain the level of function found at admission or to make minor improvement relative to a medical rehabilitation program through the use of only one additional modality or part of rehabilitative services such as therapy for physical reconditioning, limitation of deformities, etc.

The previous points are not intended as arguments for the exclusion of programs from National Health Insurance coverage such as home health care or for single service clinics providing components of rehabilitation like speech clinics or physical therapy clinics. What is intended is an articulation of differences between types and levels of care in the health care system used by disabled people.

All types of care mentioned should be covered but their utilization should be managed to assure use for purposes to which they are relevant or designed to serve.

A distinction between health care including medical rehabilitation and long-term care including nursing home care and community care should rest on the difference between an active medically-directed program with comprehensive services offered which makes substantial active changes in the functional ability of the patient, and those programs of supportive services which are directed to maintaining functional ability and assisting the disabled in dealing with environmental problems. Continuous supportive systems of care are indeed necessary for some severely disabled persons who have residual impairments in bodily form or function who cannot necessarily perform all daily living functions unassisted. Medical rehabilitation, on the other hand, improves the ability of the disabled person to increase physical or mental functional capacity by reducing the impairments, improving the physical condition, improving endurance for activity, strengthening physical capabilities, and substituting for missing parts or functions, etc. Supportive systems such as home care programs of health and social services which follow such active medical rehabilitation enable a functional status to be maintained and may also provide for further personal independence through the use of external supports such as attendant care, revisions of the home setting, the maintenance and repair of assistive devices such as wheelchairs, and even vocational training and placement services. These systems of medical rehabilitation and home care and assistance are essential to achieve the goals of rehabilitation. Both systems should be supported and the two systems should be integrated resulting in a continuous program of care. To assure this, medical rehabilitation hospitals and facilities should be encouraged as sponsors and managers of home care programs.

C. Inpatient Medical Rehabilitation -- (1) Number of Facilities; (2) Average Length of Stay; (3) Cost; (4) Problems with Present Third Party Payments; and (5) Benefits.

1. Number of Facilities

It has been estimated by an analysis of the American Hospital Association, 1975-1976 listing of hospitals that there are only approximately 430 rehabilitation hospitals and rehabilitation units in general hospitals. This listing is based on self-identification and no objective criteria were used to determine if the activities were truly comprehensive medical rehabilitation programs. Most of these inpatient programs are accredited by the Joint Commission on Accreditation of Hospitals ("JCAH"). Of this group, those that are accredited by both the JCAH and the Commission on the Accreditation of Rehabilitation Facilities ("CARF") include 100. Of this group of 100 facilities, 45 are freestanding rehabilitation hospitals with inpatient beds and 55 are units within regular acute general hospitals. There are approximately 5000 beds in these accredited facilities with a capacity of approximately 60,000 patients per year if one assumes that the average stay is about 30 days. The programs which are accredited by both the JCAH and CARF fulfill requirements of conventional hospitalization; in addition, they meet the CARF criteria for an organized, complete medical rehabilitation program. The criteria of CARF include the specification by each facility of expected goals or benefits of care for each patient and the designation of a comprehensive and an integrated program of multi-professional services under physician direction to achieve such goals. Presently, JCAH accreditation (but not CARF) is necessary for reimbursement by Medicare in many facilities and is used similarly by some state agencies.

2. Average Length of Stay

The average length of stay ("ALOS") for these hospital programs is between about 30 to 40 days. It is longer than the ALOS in the general hospital because patients have more complex and intensive care needs. This medical rehabilitation hospital stay generally includes a 10 day sub-acute care phase in which some rehabilitation designed to minimize disabling conditions is utilized. The disabilities most frequently treated include the spinal cord injured person with quadriplegia or paraplegia; stroke; individuals with amputations resulting from disease like diabetes or cancer, or resulting from trauma; persons with impairments particularly those associated with severe arthritis or fibrositis; cerebral palsy and other birth defects in children; muscle disorders including muscular dystrophy and other movement disorders resulting from nervous system disease such as multiple sclerosis, Parkinsonism in older persons, etc. Blindness and deafness are included in special programs for such persons. Medical rehabilitation of the spinal cord injured involves an average of 10 to 12 days of sub-acute care, and 90 days of medical rehabilitative care for the paraplegic; 120 days for the low quadriplegic and as much as 250 to 270 days for high quadriplegics with breathing impairment (only a small percentage). All of the other medical conditions leading to severe disability generally involve an average of only 30 to 40 days of care including a limited sub-acute phase. Some involve fewer than 30 days such as the low back impairments that are unrelated to any spinal cord injury. This information comes from professional standards developed by the American Academy of Physical Medicine & Rehabilitation for the AMA and DHEW. It has been corroborated by the Association of Rehabilitation Facilities in recent surveys. The PSRO material is available and will be supplied upon request.

3. Cost

The cost per day of an inpatient medical rehabilitation program including routine and ancillary services is not very dissimilar from general acute hopsital daily costs. Some additional costs in medical rehabilitation hospitals not included in general acute care daily costs are the substantial number of ancillary and allied health professional services and sometimes surgical costs. The cost data are from data developed at the Texas Institute for Rehabilitation Research in Houston in a cost survey based on standard cost accounting, see Document B. The Texas Institute is a special rehabilitation hospital and rehabilitation research facility. These cost data have been compared to other facilities including those in Chicago and New York and while they are somewhat lower than those in other similar institutions, this is because of differences in labor, time of admission in - respect to onset of illness and injury and other factors. They are nonetheless representative generally of the costs of care in comprehensive medical rehabilitation first-admission inpatient programs. The average cost per patient per stay treated in 1976 was approximately $8000. The average cost range is from $10,800 for quadriplegics and $8700 for paraplegics to $7500 for stroke victims, $6000 for arthritics with extensive skeletal deformities, and $5000 for amputees. Maximum costs for the most severely disabled persons including those with many complications and need for extensive reconstructive and repairative surgery for bed sores, kidney stones, etc. may be 6 times these numbers. The stays are longest for high quadriplegics, least with children for muscle disorders. Obviously, as one can see from the column "Other" in Document B, a significant number of cases are of a variety of other conditions such as Parkinsonism, etc. which are not indicated.

With an average length of stay of 40 days and with a mix of patients perhaps more characteristic of the average inpatient rehabilitation facility (fewer quadriplegics, particularly high quadriplegics), using the average cost of 1976 of $8000 per stay, the average per diem would be in the range of $200. This cost includes all ancillary professional and technical services, medications, surgery, besides routine hospital bed, board, and nursing costs. This estimate of course is highly biased depending upon the mix of disabled patients according to their severity, complications, age before admission to a rehabilitation facility which accounts for differences among facilities.

4. Problems Under Present Third Party Payment Programs

Attached is Document C which is a document submitted to the Civil Service Commission detailing problems with rehabilitation hospital reimbursement under a number of private plans offered to Federal employees. Some policies define hospital as an institution providing medical and surgical care including emergency rooms. This excludes most rehabilitation hospitals since surgical services are not offered in most and none have accident emergency rooms. Other insurance policies specifically exclude rehabilitation care from their hospital benefits which have been negotiated in order to achieve cost premiums competitive with other plans not offering such services or benefits. Medicare specifically includes rehabilitation hospitals in its definition of a hospital. In Medicare, however, there was originally a failure to recognize rehabilitative services as a hospital treatment program despite the inclusion of the term rehabilitation hospital in the definition of "hospital". The confusion existed because no definition of rehabilitation care or services existed in the Medicare statute. To a large extent, this problem was solved through intermediary guidelines defining medical rehabilitation in 1973. The definition is similar to that adopted by the AMA and recommended by the American Academy of Physical Medicine & Rehabilitation. See Document D for the AMA-American Academy definition and the Medicare guidelines. These guidelines should be part of a statutory definition, however, since they have not been enforced evenly by intermediaries.

The basic problems with Medicare in 1977 are: (1) its 29 month waiting period before the disabled are eligible for services of any kind resulting in utilization at inappropriate times after the disability has reached a fixed stage or many preventable complications have developed (also, the person has to be SSDI eligible); (2) the 60-90 day limit on inpatient care which is too short for the severe disabilities such as quadriplegia and paraplegia, multiple amputees, etc; and (3) the failure of fiscal intermediaries to follow the 1973 guidelines defining rehabilitation, resulting in denials of reimbursement for typical rehabilitation services such as occupational therapy, psychological and social services, special equipment and prosthetic devices.

The basic problem with Medicaid is the very short day limits on inpatient hospital care in most states -- 20 to 30 days maximum. This period is far too short to cover most inpatient medical rehabiltiation cases.

5. The Cost Benefit Value of Inpatient Medical Rehabilitation

The document attached as Document A cites a number of studies dealing with the benefits of comprehensive medical rehabilitation programs, involving inpatient care as well as outpatient follow-up. Work done as part of the "Comprehensive Needs Study" dealing with severe disability and cited on page 6 of Document A indicates that for the major disabilities treated in medical rehabilitation hospital programs (stroke, spinal cord injury, arthritis and amputations), functional ability increases from 35% of normal at admission to 70% of normal at discharge. After a 2-3 year follow-up, this improvement has increased to 75%. Document A at page 6 also notes that 70% of all patients served in comprehensive medical rehabilitation inpatient programs return to work. (Studies from Mt. Sinai and the Rehabilitation Institute of Chicago and the Texas Institute for Research & Rehabilitation support this -- see page 12 of Document D for citations.) These same studies show lifetime savings of $60,000 per spinal cord injury patient treated in these programs. In those cases, the cost benefit ratio is on the order of about 7-to-1 using the Texas average cost figures for care.

D. Outpatient Rehabilitation Care -- (1) Facilities Providing It; (2) Services Covered; (3) Costs; (4) Problems with Third Party Payments; (5) Benefits.

1. Facilities

Most all of the 100 CARF-accredited inpatient hospital programs providing medical rehabilitation services also provide such comprehensive programs of care on an outpatient basis. Outpatient care is important in medical rehabilitation inpatient programs since early return to the home is a necessary part of a medical rehabilitation prgoram. In addition to the 100 hospital outpatient programs, there are 110 rehabilitation facilities which are accredited by CARF which are "free-standing" outpatient rehabilitation facilities not in hospitals or having inpatients. Thus, 210 outpatient facilities are accredited now by CARF with the 100 hospital programs also being JCAH accredited.

There are some 250-300 hospitals which the American Hospital Association"Health Care Guide for 1976" lists as having outpatient rehabilitation departments. These programs are not CARF accredited , but are JCAH accredited prorams; however, it can be expected that CARF accreditation could eventually be met by most of these programs if it were required. Thus, another 200 programs might be added to the 210 presently CARF-accredited.

The estimates in this section are drawn from the AHA "Guide to Health Care for 1975-1976"; the American Rehabilitation Facilities coded membership list and the CARF listings of accreditations.

2. Services

An outpatient rehabilitation program in a hospital or other facility is different from a speech pathology clinic, for example, because, like the inpatient rehabilitation program, it has a comprehensive and integrated program of services provided under a physician-directed plan and including physical therapy, occupational therapy, medical and social services, psychological services, speech and audiology services. Other therapies are also offered such as inhalation therapy.

Obviously, each patient may not need all services. His service needs depend on his disability status and physical condition and complications. However, each needs physician evaluation and management and usually several other professional services ordinarily directed by a physician.

3. Costs

The costs of these programs are generally determined by the costs of each unit of service. Physical therapy costs per unit of service in 1975 were about $16 and speech pathology services slightly higher. Skilled nursing services are somewhat lower than the therapies. (See Document D, page 10, which includes 1973 data which has been increased for reasons of inflation.) (Those figures are corroborated by data from 8 rehabilitation facilities in Connecticut.)

4. Third Party Payment Problems

Under private insurance, only the hospital outpatient programs are generally recognized as providers of a limited number of specific services. Speech pathology, occupational therapy and psychological services are not recognized in many private insurance programs including Blue Cross-Blue Shield policies. Such services are specifically excluded from both inpatient and outpatient programs.

Under Medicare, both the hospitals and other rehabilitation facilities are recognized providers of outpatient rehabilitation care under Part B. The facilities must meet Medicare conditions of participation including recordkeeping, reporting and professional staff requirements. However, while hospitals are reimbursed for the entire rehabilitation program, the other rehabilitation facilities get reimbursed for only physical therapy [illegible] speech therapy as well as for physician services. Nursing services, occupational therapy, medical social services and psychological services are not covered despite their inclusion (with the exception of psychological services) as home health and nursing home benefits.

5. Benefits

Comprehensive outpatient rehabilitation care is a necessary adjunct to the inpatient program and both are necessary to achieve the improved functional ability composing the benefits of rehabilitation, vocational success, and cost savings of the care cited previously under B 5 in this paper.

E. Community-Based Long-Term Care Services

Attached as Document E is a very good, brief paper documenting the need for community-based health and social services to enable disabled individuals to function more independently (in their own homes rather than in institutions). The patient population analyzed were discharged from an organized medical rehabilitation program and were determined to be most at risk of institutionalization. Two-thirds of the patients surveyed were returned home and one-third institutionalized in long-term care facilities -- nursing homes or chronic disease hospitals.

Major variables affecting whether community care or long-term care facility care were utilized were a family's willingness to care for the person at home and the progress in terms of self-care which the patient made prior to discharge. Obviously, these factors serve to limit home care costs, i.e., the family would provide attendant type care at no dollar cost. The average cost over 6 months for home care services for the population returned home was $72 per week in 1973 dollars, or about $10 a day. This is substantially less than the cost of any level of nursing home care -- $30 to $50 a day in 1976 dollars. The services provided were personal care services ($4 per hour); homemaker and housekeeper ($3 per hour); escort service; and physical therapy and nursing care at $12.58 and $10.86 per visit. All figures are 1973 dollars and therefore have to be increased by about a third to make the dollars equal to 1977 dollars. Still, the cost per week would be about $95 or about $14 per day. See pages 9 and 10 of Document E for details.

Some of the services provided are traditional, Medicare covered, health services such as home health nursing care and therapy. However, other services such as attendant or personal care, homemaker services and transportation are not. Added to these services might be nutrition and home meal programs. A home care program of this nature, while it might well be treated as long-term care and not part of a health care program including medical rehabilitation, should be integrated with medical rehabilitation care. To achieve this goal, medical rehabilitation providers should be authorized to manage home care programs.

F. The Total Universe of Need for Medical Rehabilitation Care and Some Rough Cost Estimates of Including It As a Benefit

Present estimates of those with severe disability who could utilize medical rehabilitation care are 2.5% of the population or approximately 6 million people. Paper by W. Spencer, D. Stock and J. Cole, "Medical Rehabilitation of the Chronically Ill", 1976, for HEW (ASPE). This is consistent with estimates of the "Comprehensive Needs Study". Spencer estimates new cases each year at 10% of the total or about 600,000 cases. This is consistent with general health statistics on new cases and with a study by Kottke evaluating those in acute hospitals of the University of Minnesota for rehabilitation services needs. Kottke found 20% of the acute hospitalized population to need component medical rehabilitation services and 2% to need comprehensive rehabilitation programs.

The existing capacity of comprehensive medical rehabilitation programs may be equal to serving about 10-20% of the 600,000 newly disabled every year, or about 60,000-120,000 per year now. This figure comports with recent spinal cord injury data showing a total of about 10,000 new cases each year, but showing existing spinal injury programs and facilities having the capacity to provide comprehensive care for only about 10% of this number based on estimates of the professional membership in the American Spinal Injury Association and Health Insurance Association data regarding the American Institute of Highway Safety. "The Costs of Spinal Cord Injuries", December 15, 1976, Vol. II, #20. If 60,000-120,000 people were served, at an average of approximately $8000 per case, the total cost of medical rehabilitation would be about $500 mil. to $1 bil. per year. Outpatient costs at a maximum of $750 per year for 120,000 persons would add up to $90 million per year.

Summary:	Total
Inpatient Medical Rehabilitation for the Severely Disabled at $8,000 per case for 60,000 - 120,000 persons	$500 million - $1 billion
Outpatient Follow-Up at $750 per year for 120,000 persons	$90 million
Total-----------	$590 million - $1.1 billion

Referral to an inpatient rehabilitation program would be initiated by the first utilization review in hospitalization at 15 days as a requirement of reimbursement for services to the severely physically handicapped facing or having a disability. This control might increase demand for services but would clearly save long-term costs of extensive general hospitalization or long-term care institutionalization.

Since Medicare, Medicaid, Vocational Rehabilitation and the Crippled Children's program sponsor some of this care now, the $590 + million estimate is not a net figure. The net increase over existing Federal commitments would be much less than $590 million. If the Texas Institute of Rehabilitation Research experience cited in Document B is representative, the net additional Federal cost might be only 60% of the total costs since 40% of revenue is now federal outlays. 60% of $590 million to $1.1 billion is $360 million to $700 million.

Costs of the home care program are not shown here. Obviously, they might reach $5000 per case per year if utilization for a full year were as indicated by Document F.

The documents referred to in this statement may be found in the subcommittee files.

National Easter Seal Society for Crippled Children & Adults
2023 West Ogden Avenue Chicago, Illinois 60612

Child - Male - 2½ yrs.
Diagnosis - Spina Bifida
History - Referred from Children's Memorial Hospital where surgical procedure for spinal closure and for a shunt were performed.
Typical length of stay, 3 yrs. (This report is of the first year)

Physical therapy	150 Units*	@ $20 per	=	$3,000
Occupational therapy	100	15 per	=	1,500
Speech therapy	50	15 per	=	750
Audiological Evaluation	2	40 per	=	80
Psychological Evaluation	1	75 per	=	75
Medical Evaluation and Management	17	40 per	=	680
Transportation	150	5 per Round Trip	=	750
Length of treatment	1 year	Total Cost	=	$6,835

*Unit = 1 hour

Tradewinds Rehabilitation Center
Gary, Indiana
Frank Rosenbaum, Executive Director
219/949-4000

Child - Female - 3½ yrs.
Diagnosis - CP
History - Referred from Children's Memorial May, 1976
Started at Easter Seal July, 1976, Discharged January, 1978.

Speech therapy	51 Units*	@ $17 per	=	$ 867
Occupational therapy	52	17 per	=	884
Group therapy	86	4 per	=	344
Mother's group	6			
Standing Table				200
Swimming	20	2 per	=	40
Length of treatment	18 mos.	Total Cost	=	$2,934

*Units - per visit of 1/2-3/4 hr.

Willett Rehabilitation Center
Betty Johnson, Program Director
312/287-0222

Child, Female, 1 yr. 8 mos.
Diagnosis - Meningocele, hydrocephalus, post-op
History - Hospitalized intermittently for 3 months. Referred to Easter Seals with Rehabilitation problems of lower extremity paralysis, developmental delay and speech and language deficit.

O-3 intervention (multidisciplinary)	22 Units*	@ $20 per	=	$ 440
Occupational therapy	22 Units**	15 per	=	330
Physical therapy	78	15 per	=	1,170
Speech therapy	22	15 per	=	330
Length of treatment	1 year	Total Cost	=	2,270

*Unit = 2½ hours
**Unit = ½ hour

Easter Seal Treatment Center
Elgin, Illinois
Peggy Muettertles
312/742-3264

Child - Male - 3 yrs
Diagnosis - Cerebral Palsy - Blind
History - Previous Hospital Treatment - Ft. Worth Children's Orthopedic Clinic
First seen 12-9-76 - No hospitalization to date
Out-patient services started at Easter Seals 12-29-76

Physical therapy	172 Units*	@ 6.50 per	=	$ 881.70
Occupational therapy	186	6.50 per	=	1,812.30
Speech evaluations	3			22.50
Speech therapy	186	6.50 per	=	1,812.30
Audio Screening	1			10.60
Length of treatment to date	15 mos.	Cost to date	=	$4,539.40

*Unit = 15 minutes

Tarrant County Rehabilitation Center
Fort Worth, Texas
Robert Scott, Executive Director
817/336-8693

Child - Male - 4 y
Diagnosis - Spina Bifida
History - Surgery for closure of the back and a shunt in 1973. Bilateral hip surgery in March of '76, sub-trochanteric osteotomy, illiopsoas tenotomy and adductor tenotomy. Referred to Easter Seals for evaluation in Oct. '75 and referred again for treatment in January, 1976.

Re-evaluation	3 Units*	@ $132.00 per	=	$ 396
Physical therapy	86 Units**	8.50 per	=	731
Occupational therapy	97	9.00 per	=	873
Speech therapy (group)	357	.51 per	=	182.07
Length of Treatment	1 year	Total Cost	=	$2,182.07

*Evaluations - psychology - $54, physical therapy $17, Occupational therapy - $18, Speech therapy - $24, social service $19, (if audiology added it would be an additonal $27.)
**Unit = ½ hour

Dallas Society for Crippled Children
Dallas, Texas
Loyd Martin, Executive Director
214/358-5261

Child - Male - 3 yrs. 4 mos.
Diagnosis - Spastic double hemiplegia
History - Initial evaluation at 6 mos. in an evaluation center. At 12 mos. referred to Easter Seal for comprehensive evaluation and therapy.

The program described below is for '76-'77 only.

Re-evaluations	2 Units*	@ $132 per	=	$ 164.00
Physical therapy	99 **	8.50 per	=	841.50
Occupational therapy	155	9.00 per	=	1,395.00
Speech therapy (group)	351	.51 per	=	178.05
Speech therapy (feeding)	26	8.25 per	=	214.50
Length of Treatment	1 year	Total Cost		$2,793.05

*Evaluations - Psychology $54, PT - $17, OT - $18, ST - $24, Social Services - $19, (If audiology added it would be an additional $27)
**Unit = ½ hour

Dallas Society for Crippled Children
Dallas, Texas
Loyd Martin, Executive Director
214/358-5261

Mr. ROGERS. Thank you very much. That was a very helpful statement.

Ms. Cauffield, we are pleased to have you with us.

STATEMENT OF MARGARET CAUFFIELD

Ms. CAUFFIELD. I am Margaret Cauffield and I live at 1311 Delaware Avenue SW, Washington, D.C. I have osteogenesis imperfecta, commonly known as the brittle bone disease, which originated long before I was 18 years of age and which will continue indefinitely and has constituted a substantial handicap.

With the exception of impaired intellect, the definition used by the Developmental Disabilities Office in its brochure, "What Are Developmental Disabilities?" describes me and other with osteogenesis imperfecta.

I represent a group of families and individuals in the District of Columbia, Maryland, and Virginia who are also affected by osteogenesis imperfecta and, in a larger sense, all those in this country who have this disorder.

I came today to urge the broadening of the definition of developmental disability to include all disability categories if the individual meets the criteria recommended by the majority report of the National Task Force on the Definition of Developmental Disabilities, a task force mandated by Congress October 4, 1975. Members of the task force voted for this broadened definition at the rate of more than two to one.

The task force was directed to conduct an independent objective study to: (a) Determine if the basis of the definition of the devolopmental disabilities, with respect to which assistance is authorized, is appropriate and to the extent that it is not, to determine an appropriate basis for determining which disabilities should be included and which disabilities should be excluded from the definition; and (b) the nature and adequacy of services provided under other federal programs for persons with disabilities not included in such definition.

Try as I have, I cannot find evidence that the task force addressed part B of that mandate. We insist, therefore, that the task force did not complete its job and should be reconstituted in order to conduct the investigation into the adequacy of services for those who are now excluded by present DD legislation. Parents of children affected by osteogenesis imperfecta could testify to the discrepancy in the adequacy of programs for their children compared to those who are served under the DD programs.

To be specific in just one instance, mothers have told me how their osteogenesis imperfecta children have been turned away from swimming programs reserved for those who are developmentally disabled. Swimming is the best and perhaps the only means of exercise for the child affected by osteogenesis imperfecta.

It is especially important for a child's recovery after weeks, perhaps months, in traction and casts. Many can walk in the buoyancy of a pool who could not otherwise bear weight on their fragile limbs. Denial of such beneficial programs to these handicapped children is not acceptable.

Our mothers are continually searching for schools, physiotherapy, swimming pools for handicapped. How often I have heard, "There are many services available for mentally handicapped children but not for my OI-affected child." Parents of OI children do not have access to the direction and advocacy of the DD programs, and their queries about what is available under the DD programs are often brushed aside. Separate is not equal in our experience.

The child with osteogenesis imperfecta is often above average in intelligence and does not need special school curricula. The OI-affected child needs early physical intervention and access to education to reach optimum development of his or her assets. DD services for these children would avert the lengthy delay many of us experienced before vocational rehabilitation services were provided. In my own case, that was at age 34.

Again, I urge adoption into H.R. 11764 of the broadened definition of developmental disability as recommended by the majority report of the definition task force.

I have two articles and a brochure on osteogenesis imperfecta which I would like to insert into today's record.

Mr. ROGERS. Without objection, it is so ordered.

Ms. CAUFFIELD. I thank you for the opportunity to make this presentation. I do admire your ability to pay attention for these many hours. Thank you.

Mr. ROGERS. Thank you so much. We appreciate your being here and your making the effort to give us the benefit of your thinking and it is helpful to the committee.

Ms. CAUFFIELD. I have copies for all the members of the committee too.

Mr. ROGERS. That will be fine. Thank you so much.

Now, Ms. Connors.

[Testimony resumes on p. 320.]

[Attachments to Ms. Cauffield's prepared statement follow:]

Children with Osteogenesis Imperfecta

by FRANCES M. DUBOWSKI, R.N.*

Because there have been no guidelines for nurses in the care of osteogenesis imperfecta children, there is a profound need for bringing to light the errors and ignorance in the care of these intelligent, fragile individuals. Awareness of this crippling disease was created in 1968 by a magazine article in which a mother wrote of her anguish and inability to cope with a child so helpless and totally dependent upon her. As an outgrowth of this article the first clinic for the care of these children was organized.

I had my first encounter with an O.I. birth during my nurses' training at Cook County Hospital, Chicago. This birth created an aura of fear, clamped mouths, and averted eyes. Everyone avoided the mother. The delivering physician was curt, spoke in short quick sentences, and left her room immediately. She left the hospital without seeing her baby. The infant remained in our hospital for nine years because no one knew that he could live in the outside world. His record read "forty-three fractures (plus) of the upper and lower extremities and ribs."

Many years later I came to work in an orthopedic hospital for crippled children where, on my first day, my first bath assignment was that of a 9-year-old, 23 pound, 19½ inch youngster with an adult voice. His record read "fractures at birth 200 plus, too numerous to count." On this morning he had already been propped up in a carrier seat, had had his breakfast, and was stitching on a piece of embroidery.

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*Nurse Consultant to the Osteogenesis Imperfecta Research Project, Shriners Hospital for Crippled Children, Chicago.

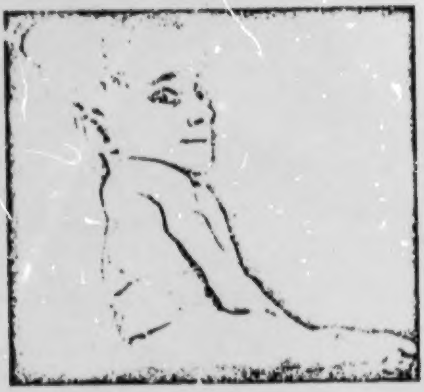

FIGURE 1. Thirteen-year-old child with osteogenesis imperfecta.

As I approached with the bath water, I heard the instructions, "Nurse, don't lift me or touch me till I tell you how." You can be sure I listened. If after reading this article you will remember only this, then I will feel that this article has been worth my efforts. Along with the need to *respect the child's instructions*, a close observation of the parents and their handling of the child upon admission is of great value. Parents live with this disease 24 hours a day and have developed special skill with their child's needs. Once I heard a snap of a femur when a co-worker changed a diaper. I also have heard a snap when blood was drawn from a child with O.I. Yes, it was the fracture of a humerus.

NATURE OF THE DISEASE

Osteogenesis imperfecta is a hereditary disease involving generalized connective tissue. It is thought to occur in two forms, congenita and tarda. In our clinic at Shriners Hospital for Crippled Children we observed many variations and for this reason chose to classify our children as severely affected, moderately affected, and mild. The nursing care for each of these categories calls for gentleness and centers on safety and prevention of fractures and deformities. I shall confine my writing mainly to the care of the severely and moderately affected since these two groups are so frequently hospitalized.

O.I. is characterized by thin broken bones, blue sclera, poor teeth, short stature, and scoliosis in 70 per cent of all affected children. Other signs in the severe form are triangular facies (generally), hyperpyrexia, excessive diaphoresis, easy bruising, recurrent epistaxis, and constipation.

Temperatures taken morning and evening for 30-day periods show that the temperature of the child with severe O.I. remains 1 to 2 degrees above normal. This is demonstrated by his need for less clothing, few or no covers when sleeping, and a greater fluid intake than other children.

CARE MEASURES

CLOTHING. This should be lightweight, nonconstricting, and void of ribbons, buttons, pockets, or ruffles. Zippers should be provided rather than buttons. Many fractures have occurred from catching an arm or leg between the crib rails. A padding to keep the extremities within the crib is a must.

DIAPERING. In changing the child's diaper, one must lift the child by his buttocks and, in a sweeping motion with the upper arm, support and cradle the legs while placing the diaper. Never lift the legs at the ankle area, since this can cause fracture of the long bones and the feet. Heavy, thick diapers can constrict, so use of these should be avoided.

BATHING. It is beneficial to allow the child to be bathed in a small tub or basin lined with a heavy towel, except where casting prohibits. An open-mesh, plastic clothes basket can be set into a larger tub, to give security to the child. The basket can be lifted in and out with the child in it.

FEEDING. At feeding time the nurse can cradle an infant on a pillow, with a comfortable amount of pressure. The older child can be placed in a portable seat-carrier, the type used for toting from place to place, with a soft strap across his middle, since any chest constriction could fracture the ribs. For a child in a spica cast, the upper portion of the body should be slightly elevated, or preferably the child can stand in a table-type walker.

The preschooler or school-age child would prefer to sit in a small wheel chair and feed himself. A pillow to sit on can prevent trauma and skin breakdown. The legs must not be allowed to hang over the edge of the wheel chair, as fracture of the femur is most common. The legs should be supported in flexion by a padded board.

The susceptibility of these children to U.R.I.'s, their chest deformity, and their poor teeth require an upright position at feeding time. They are usually picky and slow eaters, and since their stomachs are crowded up into the chest cavity, small frequent feedings are encouraged.

The occurrence of excessive diaphoresis showing an abnormality in energy metabolism requires adequate or increased caloric and protein intake. These children are always thirsty and should be allowed to drink as much as they want. They need only normal amounts of calcium, but generally dislike milk. Adding flavoring to milk, giving ice cream and puddings, and the use of milk in cooking can help supply the amount required. There are no hard and fast rules about diet, but one should make an extra effort to tempt the appetite.

USE OF THE BEDPAN. These children have an extreme fear of being handled and may not ask for the use of the bedpan. Since they do not walk, their weak buttock and leg muscles cannot support them while on the bedpan. They should be lifted gently by the buttocks, with the legs supported by a pillow. If bedwetting occurs, skin care, using water and a mild soap after each episode, can help in preventing rash and irritation to the skin.

FRACTURE CARE

Fracture of Upper Extremity

Many fractures in these children are cared for at home by the parent. There is a snap, a cry, and the child exhibits pain. The parents wrap the extremity with an elastic bandage, soothe the child, and may or may not make a trip to the hospital.

When a fracture of an upper extremity occurs, the child will most often prefer to hold that arm firmly against himself, with the opposite arm. Callus formation takes place in a few days. A triangular bandage or stockinette sling can be applied, but a long arm cast should be avoided. The weight and pressure of the cast would only serve to cause a fracture above the cast, and possibly fracture of the ribs. All fractures should be checked frequently for color, circulation, sensitivity, and movement. Apply soft padding to the axillary region to absorb excessive perspiration.

Fracture of Lower Extremities

In these cases the child is delivered to the hospital, usually with an elastic bandage type of wrapping to ease transportation. X-rays are taken, and a long leg cast applied in the older, moderately or mildly affected O.I. child. If a long leg cast is applied to the extremity of the severely affected child, there is a strong possibility of a fracture just above the cast. Therefore a hip spica is necessary to insure complete support to the entire leg.

The cast should be neatly trimmed and should not rub up against the protruding chest. The edges should be free of loose plaster, covered with a flannel-type tape, to prevent excoriation of the skin. The edges around the pubes and rectal area should be taped and then covered with plastic wrap to keep moisture out. Some physicians have applied a

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double spica or casts to both legs, even if only one is fractured. This facilitates the child standing in a few days and decreases the chances of trauma to the uninjured leg by the weight of the cast.

Our physicians do not apply short leg casts, but if this is done, the parent or nurse must use extreme care in handling the child since the weight of the cast could cause fracture of tibia and fibula at the proximal end.

Children in casts of the lower extremity should have a regular check of the covering on the feet. Sheets and spreads should not be tucked in tightly under the mattress, which would cause pressure on the toes.

CARE OF CASTS. One cannot emphasize strongly enough the importance of good cast care. This eliminates the removal of the cast before healing is accomplished. Although O.I. bone develops callus more quickly than normal bone, the bone remains subject to fracture just as it was before the initial break. A clean, well cared for cast can be kept on for the full time required, eliminating the anxiety and fear of unnecessary removal.

The importance of a dry cast is undoubtedly the one greatest factor in cast care. To avoid giving enemas, nurse and parent should persist in having the child eat fruit and drink fruit juices. It is almost impossible to keep a cast dry during an enema procedure. For boys the penis can be directed into a tube or urinal, padding with disposable diapers beneath the perineal area to catch any additional moisture. For girls the right size diaper should be used, pulling back about a quarter length of the plastic liner, folding the absorbent portion under the buttock, while taping the plastic portion to the back of her cast. The front of the diaper is tucked into the front cast opening. This can be reversed when the child sleeps on her tummy, giving the back a chance to dry, if necessary. One sanitary napkin, or more, depending on the size of the child, can be inserted into the front opening to absorb the flow of urine. Another diaper, without liner, or a cloth diaper or receiving blanket, can be placed beneath the buttocks to catch whatever moisture might seep through.

Children can be positioned at a slight incline to encourage downward flow. In the end the cast may still be damp, and for this we have used a hair dryer, under close supervision, since the skin can be extremely sensitive to heat.

Various solutions have been tried to wash casts but none have been of any value.

SCOLIOSIS. We have used the Milwaukee brace as a palliative measure. The brace is worn 23 hours of the day with an hour for bath and/or hydrotherapy. It has been the practice of our hospital to admit the child for a week to acquaint the child and the parent with procedures. During this period the brace is checked thoroughly for fit and possible pressure areas. These children are checked regularly every three months for brace adjustment and skin condition, and by the dental clinic for lower jaw protrusion and interference with tooth formation.

Fragmentation and Rodding. The challenge in this disease is the control of fractures. The fractured bones in both upper and lower extremities can curve rather dreadfully. Rodding is not done solely for cosmesis, since in spite of some severe curvatures these children can perform various tasks other than walking.

Surgery has helped in controlling fractures and correcting the deformity. It is important that these children be standing in their casts the day after surgery. Stress of the bone will increase bone growth. Rodding is most frequently done in the femur and tibia. The humerus is rodded only when it interferes with self feeding or when clothing cannot be found to fit, and the radius is done rarely because of its thinness in size. I have not known of a fibula being rodded.

Long Leg Braces. Once the bone is solid enough to remove the cast, some children are protected by long leg braces. Stress on the bones, use of the muscles, and improving circulation are of utmost importance. The child is never allowed to stand alone, but will have the immediate supervision of one or two hospital personnel and is supported and lifted as necessary. These children may never walk, but braces serve as support.

Spinal Fusion. This surgical procedure recently done on two of our children calls for positioning the child flat and using log-rolling technique as with the usual spinal fusion patient. No metal equipment was used, but soft traction has been applied.

Preoperatively these children who have increased metabolism often run an elevated temperature, but when surgery is cancelled for that day, the temperature returns to the child's normal value. Postoperatively, nausea and vomiting have not been a problem, except in one case of spinal fusion. The most frequent complications have been dyspnea and nocturnal orthopnea. Oxygen and suction equipment are routinely ordered to be available at the bedside.

Vital signs for these children are varied. Pulse and respiration are more rapid, but blood pressure remains the same as for other children. A lightweight pediatric cuff should be used in measurement to prevent trauma and fracture.

Medication. Aspirin has been contraindicated. Tylenol has been administered as a replacement.

Pre- and postoperative injection sites are usually the deltoid muscle, but though these children are mainly sitters, we have had to resort to the buttocks, the fleshier site, for any necessary daily injection.

PSYCHOLOGICAL NEEDS

These children remain in the hospital for a longer period than the usual fracture patient. This gives the nurse more time to observe and assess the level of the child's and parents' understanding of this chronic debilitating disease. They need help in developing a realistic attitude toward their life and plans for the future. Time should be provided for the child and parent to discuss their feelings openly, but encouragement must be coupled with honesty in facing the future. Many of these children have dreams of becoming doctors, nurses, or pilots, and one must redirect such dreams into the more practical vocations.

A recent survey of the adults once in our care as children reveals these positions held: secretary, editor of a newspaper, bank auditor, electronic repair man, consultant to handicapped college students, telephone sales person, and hand craft worker.

We encourage these children to attend a regular school whenever the school is on one floor or is equipped with elevators. Their active excellent minds should be developed. It has been proved that they are and can be self-supporting citizens.

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PSYCHOSOCIAL FACTORS IN LOW-INCIDENCE GENETIC DISEASE:

THE CASE OF OSTEOGENESIS IMPERFECTA

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ABSTRACT. Osteogenesis imperfecta (OI), a dominant genetic disorder, was examined in an exploratory case study of psychosocial implications. The cross-sectional survey sample consisted of 13 OI-affected adults and 21 families with an OI-affected child who were interviewed. Findings revealed numerous psychosocial concerns and problems in addition to their complex and lifelong medical problems. Specific problem areas differed according to the severity of the disease, type, and mode of genetic inheritance. The results indicate the need for local as well as national policy changes through legislation and extensions of existing services for low-incidence disease groups such as OI-affected persons. Implications for social work practice interventions call for greater involvement with genetic diseases, more aggressive approaches in case identification and service coordination, and performing longer-range monitoring functions than is usually the case.

Except in the case of popularized genetic diseases, social workers in particular and society in general have not developed much documented understanding of the often unique psychosocial problems that are inherited concomitantly with the physical liabilities of many genetic diseases. For many families with genetic disorders there are multiple lifelong medical, emotional, social, and financial difficulties that pervade their everyday existence and demand societal support systems that are not now available. The lack of these socioemotional and financial support systems is bleak testimony to the disenfranchisement of countless tens of thousands afflicted with relatively rare genetic diseases.

Among the almost 2,000 different genetic defects catalogued, the

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dominantly inherited disorders include some of the most debilitating and incapacitating diseases.* One of these is osteogenesis imperfecta (OI), which is a tragically severe disorder typical of many of the low-incidence, low-visibility dominantly inherited diseases that occur 1 in 20,000–50,000 in the general population. These diseases are not considered major enough to command much in the way of research money, social recognition, or societal concern and, consequently, lack effective lobbies and public support for special legislative and aid programs. In contrast are widely publicized diseases such as cystic fibrosis, hemophilia, and sickle cell disease which occur 1 in 500–2,500.

The purpose of this study is to elucidate the contributory psychosocial problems and special needs of OI patients, which are seen as prototypical of other severely debilitating dominant genetic disorders. These needs are related to social work and societal responses in the areas of policy development, financial support, and programmatic efforts that are required to cope effectively with the problems generated by these diseases.

Familial cases of osteogenesis perfecta occur by inheritance from an affected parent. Affected parents are very likely to have affected children, since the known transmission risk is 50% for *each* child. A person may have OI, however, without having an affected parent or relative. These cases are termed "sporadic" and represent a phenomenon consistent with the occurrence of new mutations in dominant diseases.[1] These affected individuals may then pass the disease on to their offspring following the pattern of familial cases.

Osteogenesis imperfecta is manifested in two forms: Osteogenesis imperfecta congenita (OIC) is a more severe form of the disease which is characterized by fractures at birth and extreme fragility of the bones, which sometimes fracture hundreds of times. Marked skeletal deformity, shortness in stature, brittle, soft teeth, and, frequently, progressive hearing loss are typical consequences of the disease. In contrast, osteogenesis imperfecta tarda (OIT) is characterized by onset in infancy and fewer bone abnormalities than in OIC cases. The OIT-affected person is usually able to ambulate without the aid of crutches or wheelchairs in contrast to many OIC cases. In both instances intellectual functioning remains unimpaired despite the disease.

The fact that OI begins at such an early age and is frequently marked by severely deforming, incapacitating, and untreatable skeletal abnormalities underlies the lifelong medical and psychosocial problems that plague these individuals and their families. The high risk of transmission to children underscores the fact that the problems created by the disease are likely to be continuous across generations of the same family.

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*Advances in genetic research have been limited primarily to chromosomal and recessively inherited disorders. The vast group of genetic diseases with an autosomal dominant mode of inheritance, such as OI, cannot be diagnosed prenatally, and only limited physical treatment, if any, is available.

METHODOLOGY

With few exceptions, the total available patient population in the seven-county, Twin Cities metropolitan area was included in this 1-year cross-sectional survey. The patients were selected from the medical records of the University of Minnesota Hospitals, Gillette Crippled Children's Hospital, and the Minnesota Osteogenesis Imperfecta Society. Thirteen OI adults (7 males and 6 females) with a mean age of 36 years (ranging from 21 to 62 years) were interviewed as were 21 normal parents of OI-affected children.

Home visits were made to each family. Genetic and medical histories of each affected individual were obtained prior to conducting the psychosocial interview in order to establish rapport. Personal interviews with OI adults were structured, following an open- and closed-ended questionnaire guide. The questionnaire included 21 items designed to assess general problem areas associated with OI, including intrafamilial and extrafamilial relationships, level of education, occupational status and limitations, medical needs, financial problems, and further need for social services. Subjective judgments were also made about each respondent's psychosocial functioning by the professionally trained interviewer.

FINDINGS AND DISCUSSION

Responses of OI Adults

Of 13 respondents, 11 stated that their disease affected their family relationships. Nine of the individuals spontaneously reported overprotection by their parents, which often caused friction and intensified familial anxiety. However, a third of the respondents claimed that these tendencies, together with the limitations of their disease, fostered a closer relationship with their parents. Severely affected OIC adults who underwent long periods of hospitalization during their childhood harbored feelings of rejection toward their parents. Relationships with siblings were characterized at times by embarrassment and rejection due to the affected individual's deformities and inability to participate in usual childhood activities. These occurrences frequently caused estrangement among family members. Despite these problems, half of the respondents described the effects of their disease limitation as contributing to family unity!

On dating and courtship patterns, adults with OIC frequently reported difficulties. One 24-year-old man expressed disappointment at finding his girlfriend married to a normal male following a 6-week hospitalization for a fracture. A 40-year-old woman felt that the major tragedy of her disease was the lessening prospects for a husband and family as the years progressed. All the observations were not negative: A 23-year-old man commented that while his physical deformities seemed to alienate some women, others were intrigued with his ability to overcome his handicaps and dated him.

All OI adults were interested in companionship and marriage. Only half of the women married, all past the age of 30, and they married handicapped men. In marked contrast, the three OIT males were married at an average age of 25, and they all married physically normal women.

All marriages involving an OI-affected spouse produced offspring with one exception: An OIC woman separated from her husband because *he* wanted children and *she* did not want to risk having an affected child. Despite the 1 in 2 risk for each child born to be affected with OI, the 6 married individuals had 9 out of 11 affected children. After the birth of 1 affected child all OIC parents had no further children, whereas the 3 OIT adults had more children. It is also noteworthy that 14 out of 21 sporadic families produced no further offspring after having an affected child.

Educational careers were slowed due to repeated fractures and hospitalizations. Their commitment was high, however, since all OI adults achieved a high school degree, with some finishing through GED examination. Six attended college and three graduated.

Employment opportunities and occupational security were major problems for all OI adults interviewed. Most OIC individuals found that their physical disabilities required them to undertake modest, home-based occupations such as telephone answering services, dressmaking, and home sales. Other, more ambitious persons developed their own businesses in their homes: One woman provided secretarial skills for the small community where she lived; another young man did computer programming. Those more mobile adults employed within the community tended to remain in their jobs for most of their working careers.

Limited occupational opportunities, absenteeism due to intercurrent medical problems, and the hereditary nature of the disease contributed to the extensive financial problems of almost all OI adults and their families. Expenditures for special ambulatory equipment such as wheelchairs and braces, continued medical and hospital costs, and special transportation expenses created major and unrelenting financial burdens. Family financial stress was compounded by multiple occurrence of OI in a family. Even though 11 out of 13 respondents indicated that they received social services as a result of their OI, they almost always needed additional services including better vocational and educational counseling, special transportation services, as well as continuing financial assistance.

Families with OI Sporadic Cases

Those parents who produced a sporadic OIC child were overwhelmed at the birth of their sometimes severely deformed babies, many describing their reactions as ones of shock and immobilization. Some initial reactions included anger that there had been no one knowledgeable to counsel them about the diagnosis or prognosis for their child. Depression and feelings of guilt at having produced a malformed child were frequently present, and fear that they would not be able to provide adequate care for their child was sometimes overwhelming. These reactions occasionally impaired appropriate parental functioning: One set of normal parents who produced an affected first child cut themselves off from friends and activities and concentrated all their time and energy on this child; another first-time mother became so depressed and frustrated at the extra care required by her affected child that she had to turn most caretaking duties over to her own mother.

OIT families with affected sporadic children differed in their initial reactions. Since with OIT bone deformities and fractures usually do not occur until 1 or 2 years of age, the newborn appears perfectly normal. These parents have a more gradual introduction to the disease, making it somewhat easier to accept.

When a sporadic case of OIT occurs, the diagnosis is made, and the nature of the inheritance explained to the parents, several stress-producing reactions generally follow. A parent may inappropriately assume full responsibility for the defective gene and become totally incapacitated with guilt and fear. Or, as in other cases, one spouse may blame the disorders on a defect in the other spouse's family. While genetic disorders often incur such severe marital distress and frequently later result in separation or divorce, this did not occur among sporadic families.[2]

Extended family members frequently were noted as impeding normal family interaction and overall acceptance of the affected child. One-third of the families reported denial of the disease in the family, and, at times, even rejection of the child by grandparents, aunts, and uncles. Another one-third of these sporadic families mentioned that extended family members overreacted and became overconcerned, almost obsessed with the affected child.

In contrast, one upper-middle-income family described their sporadic child's birth and familial acceptance as beneficial for the family in that it slowed down their hectic life pace and unified them to give support to the affected child as well as to each other.

Sporadic and Familial Comparisons

Problems and needs frequently differed according to the mode of inheritance of the disease. In familial cases of OI, knowledge of the disease and its risks provides a more secure, seasoned environment for the newborn OI child. Affected parents who have lived with the disease correctly assume that they can prepare their affected child for ensuing disease-related problems; however, this is not always the case. One mother attempted to compensate for the loss she experienced as a child by overprotecting and overindulging her own OIC-affected child, which is a familiar parental response.

In sporadic cases of OI somewhat different kinds of problems and concerns are faced. Giving birth to a child with OI is initially devastating for parents who have no prior knowledge of the disease. Their fears, guilt, and anticipations are limitless. Frequently, they are overwhelmed by feelings of burden and discouragement that interfere with accepting the affected child. Schild's[3] contention that the fear that one possesses a defective gene causes a momentous insult to the ego and fosters inadequate parental functioning was true initially for many parents of sporadic OI cases. There evolves a gradual acceptance and tendency among sporadic families to focus on the affected child as unique and special, setting the child apart and creating a family imbalance. In contrast, an affected child born to an affected parent is much more readily accepted into the family.

The ability of OI families to cope effectively with the consequences of the disease is, however, severely stressed as the number of affected family members increases. Familial imbalances again occur when more than one member is affected, with OI becoming the center of familial concern and activity. Those who are physically normal may feel estranged and develop psychological problems. In one family with three severely handicapped members, one physically normal girl had to assume heavy household responsibilities and faced critical identification problems that were not present among the affected siblings.

Comparisons of OIC and OIT Cases

OIC individuals face an enormous onslaught of problems consequential to their disease that are often less severe and complex among OIT cases. They must contend not only with the recurring fractures and resulting physical deformities of their disease but also with the social problems linked to their dwarfism and stunted growth.[4] As is often the case with a handicapping disease, major psychological difficulties can emerge, especially in terms of establishing a positive self-concept and self-acceptance. Physical disease and disability may also induce individuals to respond with an emotional reaction that may be more incapacitating than the disability itself.[5] Most OI adults, however, appeared self-accepting and comfortable with themselves and their deformities. The theory that physical disabilities have special and usually negative symbolic meaning was not evident in most OI individuals.[6]

Ambulatory problems also plague OIC individuals more than OITs since most are limited to using crutches or are confined to wheelchairs. Without a specially equipped car, OIC adults are severely restricted. Inaccessible public transportation and architectural barriers occasionally create a situation of almost total isolation. Metropolitan area transportation facilities for the handicapped are virtually nonexistent, and, like their small-town counterparts, individuals with ambulatory problems must depend on family, friends, or neighbors for mobility. Ironically, this dependence fosters a reluctance on the part of some potential helpers, who fear that bodily movement of an affected person may well induce fractures.

Mobility is a major consideration determining ultimate educational and occupational status and achievement. Several OIC individuals were discouraged by the inaccessibility of potential resources, and financial and architectural barriers as well led them to discontinue their formal education. This, in turn, limited their potential occupational opportunities along with the constraints associated with their mobility level. Furthermore, nearly all respondents reported being victims of discrimination as they sought employment.

The kinds of employment more easily accessible to OIC adults provide for bare subsistence income only. These earnings are not enough to cover the unrelenting stream of medical expenses. Complicating their financial situation is the fact that individuals with inherited congenital disorders are not eligible for medical insurance.

Those individuals eligible for Supplemental Security Income (SSI) benefits can receive a maximum of less than $170 per month, which is barely adequate for subsistence. This situation creates a double bind: In order to survive, one must supplement these SSI benefits; yet if one works, those benefits are either proportionately decreased or completely cut off. A young OIC woman presents a typical dilemma: She would like to gain employment in order to become eligible for federal Social Security benefits. However, if she works, her current source of income and medical coverage (a state-funded program) will be discontinued. Due to her disease, she cannot afford to be without medical coverage for even a brief period of time. She is, therefore, forced to remain unemployed and dependent on her parents. An onerous feeling remains for many OIC individuals, one of being an immense burden to their families because they are thwarted by an unaccommodating system in their efforts to become independent.

In many ways OIT individuals confront more anxiety in their lives than do OIC individuals because of their relatively normal appearance. OIT sufficiently complicates affected individuals' lives with repeated fractures, hospitalizations, and ensuing losses from work and school; yet they may appear physically normal and must compete with physically healthy individuals in school and for jobs. This competition intensifies already high anxiety levels for these persons. The tarda form of the disease does not inflict enough of a handicap on many of these individuals to warrant welfare support or special aid programs. They, nevertheless, face discrimination in trying to secure and maintain employment and in obtaining medical insurance because of their disease.

Additional Findings

Questionnaire and interview responses document the impact that a physically debilitating genetic disease has on family dynamics, social relationships, educational achievement, employment possibilities, and family finances. In contrast to another study that concluded that "OI adults . . . think alike, feel alike and sound off . . . in the same way,"[4] this survey reveals a *variety* of responses obtained from OI-affected adults. One might expect that such a disabling disease as OI would precipitate severe personality dysfunction among affected individuals. Instead, a varying range of reasonably good adaptations and compensatory measures were found. Most OI adults were rated moderate to high in their levels of ambition and anxiety. Hostility levels among OI adults were judged to be quite low. They gave a general impression of some social alientation and high dependency levels, but this is consistent with the physical limitations of their disease.

Perhaps being physically handicapped, or restricted from normal activity, allows more time for self-evaluation and self-knowledge, and a comfortable acceptance of self is eventually attained. This might account for the high levels of expressivity and moderate to high self-concept ratings of most observed OI adults.

Despite physical disability and disease-related familial and social problems, it is significant that half of the OI adults chose to marry *and* to have children. This may well indicate a quest for normalcy in a life plagued with exception. Motivation for having children varied as well. Some parents had been unaware of the high risk of having an affected child. Those who were cognizant of the risks involved gave no explanation for their motivation other than their extreme desire to have children. Schultz's[6] proposition that having a defective child intensifies parental desire for normal children was not supported in this study; quite to the contrary, the majority of sporadic families and all OIC adults had no further children after one affected child was born.

IMPLICATIONS FOR SOCIAL WORK

There is indeed ample opportunity for social workers to become increasingly involved in the field of genetics. Schild's[7] statement that geneticists and physicians—traditionally trained as academicians and researchers—have had little experience or training in dealing with personal and interpersonal relationships of their patients is a fitting call for contributions from the social work profession. As genetic services expand, it will be the social workers' responsibility not only to provide improved services but to conceptualize and identify the nature and kinds of psychosocial problems that occur as a concomitant of inherited diseases.[7]

The unmet needs of various diseases, especially those with low social visibility, should be further investigated, differentiated, and made generally known. Taken separately, low-incidence diseases such as OI represent a small population; however, in combination with the many other uncommon disorders, such as achondroplasia, Marfan's syndrome, and Ehlers-Danlos syndrome, the number represented by these low-incidence diseases grows to sizable proportions.

Social workers who become involved with genetically inherited, low-priority disease groups such as OI must assume an advocacy role and help to initiate policy and program formulations with which to assist these groups, whose unmet needs are considerable. The provision of nonpunitive, facilitative, and continuing financial assistance is a foremost priority for these families, who are denied medical insurance, excluded from most catastrophic illness coverage, and who now receive only subsistence support from public funds. A chronic disease such as OI takes a severe toll on even upper-middle-class family resources. Only generous governmental sponsorship, through direct and indirect payments, can alleviate the financial stress placed on families affected by such debilitating diseases as OI. Such public sponsorship could easily be achieved through a revised concept of need that includes as beneficiaries those who are permanently afflicted but not totally disabled and those who are financially desperate but not destitute. While the need for such a support system should be applicable to all persons affected by incapacitating disease, the need is greater for low-visibility genetic diseases such as OI because there are no sizable private foundations that can underwrite some of the special costs of treatment. If programs are available to help such individuals, they are usually piecemeal and lack comprehensive coverage.

Since most genetic diseases such as OI imply chronicity, affected individuals and their families require a life span approach to intervention rather than the more traditional time-limited approach to providing social services. In many cases, the life span approach could be

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elaborated into an intergenerational approach to intervention because of the high probability of recurrence in subsequent generations. Except for some hospitals and rehabilitation centers, the social work profession is neither conceptually nor practically equipped for dealing with such long-range considerations. A concept of monitoring-in-anticipation needs to complement the reactive concept of crisis intervention that so heavily permeates social work practice today. One prime avenue to gain access to this population of interest would be through greater social work involvement as part of a genetic team. Early, consistent support for the family could be provided as well as continuity of service as long as need exists. Such social workers can also serve to facilitate communication with medical and research personnel about the psychosocial consequences of inherited diseases.

In the case of OI patients, in particular, the psychosocial consequences of the disease were marked by more variability and positive effects than one would have expected on the basis of theory or commonsense expectation. The predictors of such variability are largely unknown, a situation that is probably true for most other handicapping diseases at this time. The observed cases of OI were characterized by many of the individual traits typical of other handicapping diseases such as shortness in stature and deformity, and thus shared similar psychosocial consequences with them. Yet, it would be a mistake to generalize this similarity without further knowledge of the configurational aspects of inherited diseases. Although this study was not comparative, it seems safe to assume that the combination of factors in OI—stunted growth, normal intellectual functioning, bodily deformity, repeated fractures, and severe dental problems, among others—provides a configuration of consequences that differs significantly from most other disease entities. Only further comparative research can begin to make determinations of different configurations of complex psychosocial responses to inherited disease.

Within the classes and types of OI disease itself there are a number of differentiating psychosocial factors that warrant the utilization of different social work practice interventions. For example, in *familial* cases of physically debilitating genetic disease it would be important for the worker to learn what meaning the disability has for the affected individuals. Focus should revolve around an acceptance of limitations and concentration on realistic goals. Family planning and premarital explorations should include concrete genetic information about the disease. In *sporadic* cases, genetic diagnosis precipitates a crisis situation, and immediate interaction and contact is often crucial.

Social workers should remain cognizant of specific familial dynamics and potential problem areas that frequently occur within families with genetic diseases. These include parental feelings of guilt and inadequacy, the tendency to overfocus on and overprotect the affected child, the propensity for marital discord and stress, and the sometimes dysfunctional involvement of extended family members. It is frequently useful to involve extended family members in genetic counseling and in promoting the acceptance of the child and his disease. This helps to establish a groundwork for continual support and encouragement for overwhelmed parents and their affected child.

Although the precise psychosocial effects were unclear, the pervasive, interlocking themes of relative immobility and continuing dependence at least have limiting effects on life satisfactions and achievements. Although the adaptations of OI-affected persons were sometimes remarkable, the constraints on their lives were evident in educational attainment, job finding, and job retention. A better developed and coordinated vocational rehabilitation service that can effectively cope with job training, job location, job retention, as well as increasing job opportunities while minimizing discriminatory practices is evidently needed.

The key to increased opportunities for OI-affected persons lies, in part, with solving the mobility problem: If physical access is impossible, then other program efforts are doomed to failure. Although there are often existing community transportation programs, they are frequently piecemeal, inadequate, sporadic, and oriented more to meeting recreational needs than those related to employment. With so many fragmented programs in existence, it is perhaps time to develop city- or area-wide coordinated transportation services that can be more responsive to a broader spectrum of public need. It would have to be guided by a new philosophy-in-practice that goes beyond promoting life satisfaction through planned events and activities and aims toward promoting independence and self-sufficiency by bringing together the immobile with their opportunities for achievement.

The often unpredictable and far-ranging psychosocial consequences and the continual drain of financial resources that are associated with most debilitating genetic diseases create a challenging opportunity for the profession of social work to find new ways to help these socially neglected families.

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AMERICAN BRITTLE BONE SOCIETY

Logo Design by **Jim Manos**, Mount Holly, N.J.

AMERICAN BRITTLE BONE SOCIETY

Brochure prepared and published by the **American Brittle Bone Society, Inc.**

The American Brittle Bone Society is a national, non-profit organization dedicated to educating the public about the seriousness of osteogenesis imperfecta and, through it, gaining the financial support needed to fund research aimed at the prevention, detection, and treatment of osteogenesis imperfecta in hopes of, ultimately, finding a cure.

Further information about osteogenesis imperfecta is free upon request.

If you would like to volunteer your assistance in promoting the goals of the American Brittle Bone Society, please write or phone.

American Brittle Bone Society
712 Dartmouth Avenue
Cinnaminson, New Jersey 08077
Phone: 609/829-6212

Photo:
Even before she had breathed her first breath, though still sealed off from the outside world by the warmth of her mother's womb, her life was already in peril.

She came into our world five years ago with multiple fractures of the skull and limbs. Since birth she has suffered eleven broken bones and stands barely 31 inches tall.

WHAT IS KNOWN ABOUT OSTEOGENESIS IMPERFECTA?

The BRITTLE BONE DISEASE, osteogenesis imperfecta, has a history that stems from antiquity. An Egyptian mummy, which dates about 1000 B.C. and is housed in the British Museum, shows proof of the disease in its bones and teeth.

10,000 to 30,000 Americans are estimated to be affected by osteogenesis imperfecta (O.I.). It strikes either sex and is found in every country.

A disease of the connective tissue, it may be inherited from an affected parent. On the other hand, due to gene mutation, an O.I. child may be born to "perfectly" normal parents.

HOW IS IT DIAGNOSED?

Drastically affected children are sometimes born before their mildly affected parent is detected. Some mild cases have never had a broken bone; however they have as much chance of passing the disease along to their children as do serious cases.

There is no lab test to detect or confirm osteogenesis imperfecta; so doctors must base their diagnoses on the patient's symptoms.

In some instances of undiagnosed BRITTLE BONE DISEASE, parents have been suspected of child abuse when inexplainable fractures or bruises have occurred.

WHAT ARE THE CONSEQUENCES?

Many tragically injured infants yearly do not survive birth; many die during their first year. Those who escape early death may live to experience numerous broken bones—sometimes with no greater stress than a sneeze or muscle cramp. Repeated fractures lead to crippling bone deformities, stunted growth, and severely curved spine with pigeon chest. Patients often spend their lives confined to bed or wheelchair.

The patient usually displays a blue coloration of the scleras (eye whites) and may be subject to corroding teeth, loose joints, hernias, bruising, heat sensitivity, constipation, and deafness.

Despite the pain, restrictions, and frustration of this critically disabling disease, the O.I. patient is remarkably good-natured and generally shows above-average intelligence.

IS THERE ANY TREATMENT?

"Rodding," an orthopedic procedure intended to straighten and strengthen crippled and crooked limbs, is the most significant corrective development to date. In surgery, an arm or leg bone is laid bare, broken into fragments, and in "shish-kebab" fashion, the pieces of bone are skewered onto a fine, metal rod.

Carefully applied physical therapy may help in strengthening the weak muscles and wasting bones of the bedridden or chairbound patient. In addition, prompt attention to deteriorating teeth may lessen pain and destruction in the mouth.

The child with this devastating disease may require lengthy hospitalizations, numerous orthopedic and dental procedures, and physical therapy. The medical expense of BRITTLE BONE DISEASE can be phenomenal and financially "breaks" many families. The toll in anguish to parents is incalculable.

THE AMERICAN BRITTLE BONE SOCIETY—Advisor/Members and Consultants

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STATEMENT OF LINDA G. CONNORS

Mrs. CONNORS. My name is Linda Connors. I am from Rockalnd, Mass. I am here today in three capacities. I am representing the Tuberous Sclerosis Association of America, the Federation for Children with Special Needs of which I am the President, and I am representing Mr. Eli Tash who is immediate past president of the Association for Children with Learning Disabilities. Mr. Tash also served on the task force for the definition of developmental disabilities. [ABT report, November, 1977.]

All of the above-named entities support the majority report found on page 9 of the ABT report, November 1977. As I understand it, this is the final report of the special study on the definition of developmental disabilities which was conducted in accordance with section 301(b) of Public Law 94–103. Mr. Tash's statement supporting the majority report is attached to my testimony and I think speaks for itself.

Mr. ROGERS. Thank you. It will be made a part of the record.

Mrs. CONNORS. As president of the board of directors of the Federation for Children with Special Needs, located at 120 Boylston Street, Boston, Mass., I have been asked by the board of directors to testify at these hearings as to the Federation's stand on the definition of developmental disabilities.

The Federation for Children with Special Needs is a coalition of all the statewide parent organizations in Massachusetts that represent citizens with disabilities. Together these organizations have approximately 26,000 members.

They are: Association for Mentally Ill Children (AMIC) (Autistic and Severely Disturbed Children); Children in Hospitals, Inc., parents and health care professionals concerned with the needs and rights of hospitalized children and adults; Massachusetts Association for Children with Learning Disabilities (MACLD); Massachusetts Association for Retarded Citizens (MARC); Massachusetts Spina Bifida Association, Inc. (MSBA); Massachusetts Parents Association for Deaf and Hard of Hearing; New England Parents Association for Visually Handicapped Children and Adults; Parents and Children Together (PACT); Parents and Friends of Cerebral Palsy and Multi-Handicapped; Prescription Parents, Inc.; Massachusetts Chapter of the Tuberous Sclerosis Association of America. See the Federation brochure.

It was unanimously voted by the Federation board of directors on February 28, 1978, to support the majority report revising the definition of developmental disabilities as defined on page 9 of the ABT report, November 1977.

Finally, I am here representing the Tuberous Sclerosis Association of America (TSAA) of which I am a founding director and myself as a parent of a 14-year-old child severely afflicted with tuberous sclerosis. TSAA supports the majority report as indicated in the ABT report, November 1977, page 9, and seeks recognition by the Federal Government of tuberous sclerosis as a developmental disability.

The Tuberous Sclerosis Association of America is a legal nonprofit tax exempt national organization incorporated under the laws of the Commonwealth of Massachusetts, with chapters in Massachusetts and New Hampshire. The association's headquarters is in Rockland, Mass.

TSAA was formed to combat the disease tuberous sclerosis (TS). The Association was founded out of frustration because of the lack of information and services available to parents and victims of this disease.

Tuberous sclerosis was once considered to be a rare disease. Now, with new and better diagnostic methods and increased physician awareness, more and more cases are being uncovered. Estimates of incidence are variable but probably range from one in 5,000 to one in 10,000 of the general population.

I have some medical support letters attached to the testimony and I hope the committee will examine them.

Mr. Rogers. Yes, we will.

Mrs. Connors. I think they are very important.

Tuberous sclerosis is a genetic disorder. Individuals afflicted with the disease are born with it. Tuberous sclerosis is characterized by one or more of the following conditions. Any one or all of these conditions may range from very mild to extremely severe. See the TSAA brochure.

First, 90 percent of the patients have convulsive seizures at sometime in their life.

Second, mental retardation is prominent in this disorder.

Third, tumors, which may occur in the brain, heart, kidney, viscera, and/or any vital organ.

Fourth, physical handicaps which may restrict the patient to a wheelchair and/or being completely bedridden.

Tuberous sclerosis has no known cause or cure and there is no current medication to combat the disease. At the present time only the symptoms of the disease such as seizures and hyperactivity and the affect of the tumors can be treated. The underlying disorder, however, is currently untreatable since we do not understand the basic mechanisms of the disease.

Tuberous sclerosis affects both males and females and may occur in all races. In its severe form, tuberous sclerosis can be very devastating, making the victim completely helpless and dependent.

Tuberous sclerosis causes developmental delay. Many tuberous sclerosis victims are substantially and chronically disabled early in life, before age 22, and are decidedly in the target population as described on page 34 of the ABT report.

Tuberous sclerosis should be considered a developmental disability because it is a disease which is already present in the unborn child and continues to be present in the individual for the remainder of his life manifesting the symptoms outlined above.

Persons and families with tuberous sclerosis suffer from a lack of meaningful human services. Integration with existing local, State, and Federal service programs is essential. Tuberous sclerosis victims and their families require a wide variety of services, including physical, occupational and speech therapy, home and institutional care, behavior modification, genetic counseling, and many others.

Tuberous sclerosis has such a wide spectrum, programs have to be modified for each individual patient. Often a tuberous sclerosis child has multiple problems and parents do not know what services are available.

For example, seizures with mental retardation with kidney problems, partial or total loss of speech with physical handicaps and/or seizures and/or mental retardation, et cetera. The severe tuberous sclerosis child places a heavy burden on the family who cares for him/her, physically, emotionally, and financially.

Early developmental intervention is important in order to provide the child with the best possible opportunities to achieve his maximum potential.

The Tuberous Sclerosis Association of America has never been funded by any State or Federal agency. Only very limited research is being carried out in tuberous sclerosis. Since tuberous sclerosis is a serious cause of mental and physical disability in a significant number of Americans and may constitute as much as 5 percent of the developmentally disabled population, we feel that basic research should be of highest priority.

In conjunction with this research an intensive campaign of public education and physician awareness is necessary since this is a potentially preventable disease. TSAA feels that under Public Law 94-103, section 109, part D, "special projects grants," that it could be and should be funded.

The Tuberous Sclerosis Association of America feels strongly that the majority report be accepted because this recommendation does not favor any of the existing consumer organizations and/or their local affiliates. By accepting the minority recommendation, Congress would actually be favoring four or more national consumer organizations that presently exist in this Nation. We feel this would not be in compliance with the full intent of the law.

Specific reference is here made to HEW publication No. OHD 76-29002, entitled "What are Developmental Disabilities?" In this booklet the following are listed: National Association for Retarded Citizens, United Cerebral Palsy Associates, Epilepsy Foundation of America, and the National Society for Autistic Children.

By holding to the minority definition, these groups benefit from federally funded literature such as this booklet while TSAA and other groups do not. Further, in applying for funding under DD these consumer groups also benefit since the the conditions they represent, as in the past, are clearly stated in the minority definition, section 2.5, page 25, ABT report.

We are aware of H.R. 11764, the "Developmental Disabilities Act Amendments of 1978," under the caption "definitions," "Sec. 102. For purposes of this title: . . . (7) the term 'developmental disability' means a disability of a person which (A)(i) is attributable to mental retardation, cerebral palsy, epilepsy, or autism."

The above-named entities that I represent do not support this definition of developmental disabilities. For reasons already stated we cannot support H.R. 11764.

We do not support Senate bill 2600 because we feel it to be too inclusive and would dilute the benefits for children and citizens that we represent.

In closing, speaking only for the Tuberous Sclerosis Association of America, we would like the record to show that should the minority report, as stated on page 26 of the ABT report, November 1977, be accepted by Congress in lieu of the majority report, as stated on page 9 of the ABT report, that part No. 1 of the minority report be amended to include the words "tuberous sclerosis."

Speaking on behalf of all those I represent, I would like to thank this committee for allowing me to present our position and some of our views on developmental disabilities.

[Attachments to Mrs. Connor's prepared statement follow:]

ASSOCIATION FOR CHILDREN WITH LEARNING DISABILITIES
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Office of Immediate Past President
6700 North Port Washington Road
Milwaukee, WI 53217

National Officers

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Professional Advisory Committee

National Executive Secretary

March 28, 1978

Mr. Raymond A. Connors, President
Tuberous Sclerosis Assn. of America
P. O. Box 44
Rockland, Mass. 02370

Dear Mr. Connors:

I understand that you and Linda G. Connors, President of the Federation for Children with Special Needs, will appear before the House Committee on Health and the Environment on April 4th and 5th, during its hearing on the Definition of Developmental Disabilities. I served on the Task Force for the Definition of Developmental Disabilities and support the majority report of the Task Force.

It is most important that we recognize the specific needs of all children with developmental disabilities regardless of the category of their disability. I hereby authorize you and/or Linda G. Connors to present my point of view to the Committee hearing.

As a matter of record, I reside in Milwaukee, Wisconsin and I am presently the Immediate Past President of the Association for Children with Learning Disabilities and a member of the Board of Directors of the Wisconsin Association for Children with Learning Disabilities.

Cordially,

Eli Tash
Immediate Past President

ET:aa

cc: Alice Scogin
Jean Petersen
ACLD Executive Committee
Jack Westerlund

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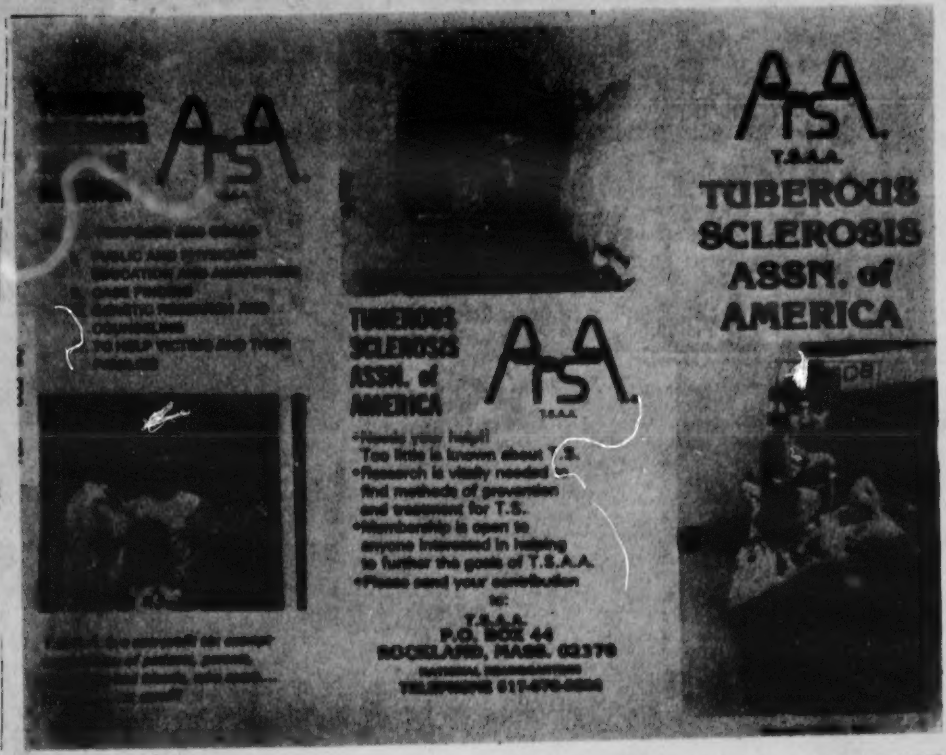

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TO HELP VICTIMS AND THEIR
FAMILIES

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TUBEROUS
SCLEROSIS
ASSN. of
AMERICA

T.S.A.A.

- Needs your help!
  Too little is known about T.S.
- Research is vitally needed to find methods of prevention and treatment for T.S.
- Membership is open to anyone interested in helping to further the goals of T.S.A.A.
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NATIONAL HEADQUARTERS
TELEPHONE 617-[illegible]

T.S.A.A.

TUBEROUS
SCLEROSIS
ASSN. of
AMERICA

Tuberous Sclerosis (T.S.) may vary from very mild to extremely severe. A mildly affected person may be entirely normal mentally and physically.

Tuberous Sclerosis (T.S.) in its severe form can be very devastating, making the victim completely helpless and dependent.

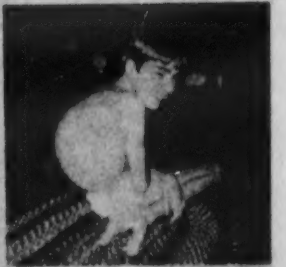
WHAT IS TUBEROUS SCLEROSIS?

Tuberous Sclerosis (T.S.) is a genetic disease; individuals afflicted with the disorder are born with it. T.S. is generally characterized by one or more of the following conditions:

I. CONVULSIVE SEIZURES
II. MENTAL RETARDATION
III. TUMORS
IV. PHYSICAL HANDICAPS

T.S.A.A.

- T.S. has no known cause or cure.
- Drugs may be used to help in the control of seizures and hyperactivity.
- There is no medication to combat the disease.
- Doctors feel there are more undiagnosed cases than there are correctly diagnosed cases.
- The importance of diagnosis is that a mildly affected parent, who is not aware of having T.S., may give birth to a severely handicapped child.
- For more information write or phone national headquarters.



Tuberous Sclerosis (T.S.) victims may have many physical handicaps and learning disabilities.

Tuberous Sclerosis (T.S.) affects both males and females and may occur in any race.

Mr. Rogers. Thank you for being here and giving us the benefit of your thinking. I think the points made are quite clear. We will take into consideration all of the suggestions you have given. We appreciate your being here.

That concludes the hearing for today. The committee will adjourn until 10 o'clock tomorrow morning in 2218. Thank you for being here.

The committee is adjourned.

[Whereupon, the committee adjourned at 5 p.m. to reconvene at 10 a.m., Wednesday, April 5, 1978.]

DEVELOPMENTAL DISABILITIES ACT AMENDMENTS OF 1978

WEDNESDAY, APRIL 5, 1978

House of Representatives,
Subcommittee on Health and the Environment,
Committee on Interstate and Foreign Commerce,
Washington, D.C.

The subcommittee met, pursuant to notice, at 10:35 a.m. in room 2218, Rayburn House Office Building, Hon. Paul G. Rogers, chairman, presiding.

Mr. Rogers. The subcommittee will come to order, please.

I might say that we do have quite a number of witnesses. What we would like to do, if we can, is ask that individual witnesses try to hold their remarks to about 10 minutes. We have a little timer here to try to remind you. Panelists can take about 5 minutes each, since the panel is presenting the same overall viewpoint. Ms. Nelson will be our reminder.

We welcome you here. We are delighted to have you and appreciate your presence.

R. Lee Henney, director of the project to Assess the Development of State Developmental Disabilities Plans, EMC Institute, Inc., Philadelphia, is here; and Dr. Ronald Wiegerink, director of the Developmental Disabilities Technical Assistance System, Frank Porter Graham Child Development Center, University of North Carolina, accompanied by Ms. Paula Hammer. We welcome you.

Mr. Henney, you are accompanied by whom?

Mr. Henney. Mr. Irwin L. Schpok.

Mr. Rogers. Your statements will be made a part of the record in full.

You may proceed, Doctor.

STATEMENTS OF R. LEE HENNEY, Ph. D., AND IRWIN L. SCHPOK, DIRECTORS, EMC INSTITUTE, INC.; RON WIEGERINK, Ph. D., AND PAULA BREEN HAMMER, DEVELOPMENTAL DISABILITIES TECHNICAL ASSISTANCE SYSTEM

Dr. Henney. Mr. Rogers, we are pleased to be able to provide this testimony on the Developmental Disabilities Act Amendments of 1978 [see p. 336]. The substantive information of this discussion represents the effort of the developmental disabilities planning councils of the 54 States and territories currently participating in the program as well as our own accumulated experience over the last 4 years. The questions concerning the evaluation and the activity of the program are contained in our report and our statistical evidence of that activity.

In our estimate, the developmental disabilities program is a program which is having an impact of increased services for its target population through comprehensive planning, influencing in accessing funds from many generic services and gap filing. EMC Institute has been involved over the last 4 years with the developmental disability program, in the creation and implementation of the Developmental Disabilities Evaluation and Information Services, DDEIS. Mr. Schpok, on my left, who will discuss the results of the analysis of the fiscal year 1978 plans in a few minutes, has been the principal architect of DDEIS. My involvement with the developmental disabilities program over the past 4 years has primarily been in the area of field activity and training, bringing a background of management training in the industrial world to the developmental disabilities community.

EMC staff members have worked in every State in the Union and the territories in implementing the comprehensive planning system and providing management training for professional staff persons of DD planning councils.

The testimony yesterday told us about the program, about the complexity of the service network and the agencies, and I will not take our precious time today, since that has been thoroughly put in the record and our statement is for the record.

To continue, if you will turn to page 4, the present DD legislation provides, in the mandated State Planning Council, for a partnership of consumers and public and private service providers to deliberate and act on the service needs of persons with developmental disabilities at the state and national level. The program uses as its major method of action the coordination and utilization of categorical service programs and the authority of collective knowledge and experience for the benefit of the individuals with developmental disabilities.

The developmental disabilities program, during its relatively short history, 7 years, has demonstrated, as the State plan analysis shows, its ability to access categorical services and obtain coordinated efforts for individuals with developmental disabilities among and between service providers. The program also has demonstrated its ability to access fiscal resources from a variety of categorical programs for its target population. The dedication, commitment and individual authority of State and national council members, staff professionals, and administrating agency personnel has been and continues to be felt throughout the nation.

The dynamics of the developmental disabilities program will be further demonstrated as these hearings continue this day. There has been an observable impact on the services available, both in quantity and quality, for individuals with developmental disabilities because of the implementation of the DD program.

The cornerstones of the current developmental disabilities program are the comprehensive planning, systems advocacy and service gap filling missions of Public Law 94–103. We would recommend that these missions not be lost with the enactment of H.R. 11764. We will review each of these missions, the status of state efforts based on the analysis of fiscal year 1978 State plans and the projected impact of the relevant provisions of H.R. 11764.

Two major concerns which we have are that comprehensive planning remain a cornerstone of any new legislative enactment and that States retain the right for program priority selection and program determination. We feel that the committee, through the introduction of H.R. 11764, has made significant improvements in the current developmental disabilities program.

We believe comprehensive planning has become an integral part of the DD program in achieving its primary mission, and this tool should remain in place in any new legislative directive. The States now have in place a comprehensive planning system which permits the councils and administrative agencies to respond to gaps in the service network in relation to realities of the political and service activities at the State and local level. Even though the four priorities identified in H.R. 11764 are the priorities of over 50 percent of the States in fiscal year 1978 State plans, it would be unfortunate to assume that all States and territories have the same service priorities. It would also impede the development of a continuum of services through strategic gap filling if the DD Act required specific priorities for all State service networks. The mandating of priorities would also dilute the dynamics of consumer/agency analysis at the council level.

Therefore, we would ask the committee to carefully examine any priorities which it would mandate for the totality of the service network, insuring that these were the total need and not average need, as is shown in the State plan analysis.

The second concern which we have is the 70-30 percent distribution of formula grant moneys. Our concern is that if 70 percent of the moneys are required for gap filling, it might, as historical evidence indicates, provide the replacement for categorical service dollars which can be accessed from existing programs for the benefit of individuals with developmental disabilities.

Analysis of State plans shows that councils and administrative agencies have been able to tap other fiscal resources for every mission area. At present, only 42 cents of every dollar spent for the DD program missions is formula grant dollars.

In our opinion, the prorated distribution called for in H.R. 11764 would decrease the emphasis on accessing other categorical service programs for the needs of the substantially handicapped developmentally disabled, thereby setting up parallel services and denying the severely handicapped access to existing programs for the total population.

We do not want this population to be considered out of the total population, but all services accessible for our population. We believe that the use of DD funds for identified gap filling is a correct one, but we believe this to be the domain of the State and local councils and administrative agencies.

Mr. Schpok will now briefly discuss the present state of the Developmental Disabilities Program as a result of the analysis of the stated plans, if you please.

Mr. Rogers. Mr. Schpok.

STATEMENT OF IRWIN L. SCHPOK

Mr. SCHPOK. Mr. Chairman, I would like to cover three things in the three major mission areas of the program. I would like to recap the intent of the DD program, provide a status report of what the States are now doing against each of those missions, and our opinions of the effects of H.R. 11764 on the current Developmental Disabilities Program. I will cover the three missions in the following order: comprehensive planning, systems advocacy, and the service gap filling mission.

The comprehensive planning mission in the current Developmental Disabilities Program is quite clear. State Planning Councils are to have a continuous and comprehensive plan for providing services to persons with developmental disabilities. Indeed, that whole plan, which covers about six areas that Mr. Humphries referred to yesterday, is a cornerstone for the actions of the council. It is meant to be a key function of the council. It is meant to be a blueprint for coordination of categorical service programs. It is meant to be a guide to the systems advocacy mission, from principle to action, in each program year.

In about 1974, a GAO report on several State DD programs concluded that comprehensive planning wasn't done. Based on a GAO recommendation the Developmental Disabilities Office started a long-range program to improve the council capability to meet the comprehensive program planning mission. The improvement program started out with a feasibility study as to whether comprehensive planning could be done at all within the framework of the program. Next a nationwide test of the comprehensive planning system was conducted culminating in the issuance of program guidelines in fiscal year 1977 relevant for the fiscal year 1978 State plan.

I think you ought to know what the States were asked to do in the fiscal year 1978 State plan. Each State was asked to provide some 275 information elements related to each of the six areas in the plan.

The National Advisory Council report is correct to say that the implementation of those guidelines was somewhat controversial. For the 10 or 12 States that were critical of guidelines, they were concerned about the amount of information or scope of information required. The 6 to 10 States that were in favor of the guidelines, were impressed by the consistency of format and indicated flexibility of use at the State level.

Despite the early controversy, the results of the effort of all States to fill their comprehensive planning mission are impressive. First, the State planning management has improved considerably over the last 3 years. This year, 70 percent of the State plans were in by the submission deadline, while in 1975, only 23 percent of the plan were in by that deadline.

This year, 95 percent, all but three State plan were submitted by the funding deadline of October 1; in 1975, only about 53 percent of the plans were submitted by that time.

The State plan analysis has nearly totally dispelled the claim that the information is not available. On a nationwide basis over 60 percent of all the information requested was provided in this year's

State plan. Seventy eight percent of the States were able to provide more than 50 percent of the information.

There were several exemplary plans. Among them were 16 States that submitted over 70 percent of all the information requested and promised to get the rest of it this next year.

These results of comprehensive planning, are the result of an integrated planning process in the councils. In one State in which the process required negotiation among generic service agencies and the council prior to the submission of the plan what was agreed upon and put into each agency plan was the commitment for over $70 million of services to the developmentally disabled.

In many States, the council members themselves have helped gather the information. Council members have been involved in key decisions on the needs assessment, identifying gaps and barriers to services, and setting up goals and objectives for this year's effort.

The planning intent of H.R. 11764 is really not clear. There are references to appropriate planning in section 101 and further references to the plan in section 133; but comprehensive planning never quite reaches the mission status it now enjoys in Public Law 94–103. If the committee wishes to capitalize on the current capability of the States to utilize a planning mission, it can do so by legitimatizing the function of the State plans and the Council's planning processes.

In our opinion, all that needs to be done is to reinstate the firm planning mission in section 101 and add language to section 133 similar to the listing of the six areas that you have heard before. Such a commitment would not require a loosening of the mandatory priorities and service funding provisions you have in H.R. 11764 your current bill, even though we believe those provisions to be unnecessarily restrictive.

In section 137, the council should have authority to review and comment on all state plans referring to persons affected by DD without reservation.

The plans themselves, because they are indeed coming across with so much information, provide us with a picture in two other mission areas of the current law: systems advocacy and the service gap filling mission.

Under system advocacy in the current law, states may respond in five areas. First, they are to protect the legal and human rights of persons with developmental disabilities, including maintenance of the protection and advocacy system; they are to insure appropriate services to persons with developmental disabilities through individualized habilitation planning and public awareness and education action; they are to promote and effect the coordination of existing services and programs; they are to promote improvement of the quality of service; and they are to monitor and evaluate the services network for the services that are related to persons with developmental disabilities.

The analysis of the State plans—and I am excluding the protection and advocacy system in this analysis—shows that State planning councils will be addressing themselves to all the mandated and optional advocacy functions in the current law. There are 500 activities reported. About 50 percent of those are dedicated to coordination; about 23 percent to promoting appropriate services through public awareness and habilitation planning; another 20 percent promoting improvement of the service quality. The councils are still lagging on the issues of monitoring and evaluation, in part waiting for the evaluation system of the current office. Only about 7 percent of the advocacy activities arc related to evaluation.

Although systems advocacy activities make up 60 percent of all reported activities, they account for only 27 percent of total dollar expenditures for the activities.

However, there is some really interesting evidence about the coordination mandate. Every DD program dollar that is being spent in coordination activities—and we are now talking about legislative and administrative policy coordination as well as the actual service delivery—is attracting about 30 cents from generic agency funds. Moreover, of the 153 coordination activities, about 36 percent are being implemented by the generic agencies themselves. That is, the agencies are taking the responsibility to see that services and program policies are coordinated.

The simple conclusion that is indicated by these plans is that the DD program is gaining financial and implementation support in the area of its coordination mandate. A similar thread runs through the other systems advocacy activities, particularly for implementation responsibilities. Nearly half of all the systems advocacy activities are the responsibility of the service agencies themselves.

If you want to think of this in another way, you can think of it in terms of the director of RSA, CSA and a few of the other major programs at the national levels sitting in one room saying to each other, "I will provide you 30 cents of my program dollar to insure that we have coordination for developmentally disabled persons." Further, the agency directors volunteer for the responsibility of implementing that coordination.

H.R. 11764 pulls together the various aspects of systems advocacy missions and does a very good job of organizing those activities in the bill. It is clear that protection and advocacy systems, promotion of legal and human rights, individualized habilitation planning, coordination and program monitoring and evaluation are central purposes of this bill.

However, it appears, from the features of section 133 and 137. that the mandated and optional methods currently available for achieving systems advocacy missions will be narrowly focused on one or two service areas, along with the dollars that will be committed to those areas.

If the committee wishes to maintain the flexible and apparently fruitful response of state planning councils to the bill's system advocacy intent, serious consideration should be given to removing the mandated choice of a service focus and program fund distribution. Section 136 might also reiterate the purpose of the bill as a State planning council responsibility.

In the current DD program the gap filling mission is handled in four ways, developing community alternatives and sponsoring institutional reform; developing prevention and early intervention programs; expanding the existing services; and demonstrating new service techniques.

The State plans show about 300 activities for the gap filling mission. The councils are accessing a considerable amount of generic service funds for these activities. In the area of prevention $13 of generic service money is being attracted by every DD program dollar. Institutional reform activities draw up to $14 for every DD program dollar. For the total set of gap filling mission activities, about 69 cents is being tapped from generic service agencies by each DD program dollar spent.

The effects of H.R. 11764 mandated service priorities and fund distribution on current gap filling activities is really not that clear. The current plan data seems to indicate less financial commitment from generic resources for existing service expansion. We can probably anticipate that a greater dedicated commitment of DD program dollars to services will be followed by a reduction of generic service dollars in the chosen area. Other programs are experiencing that same phenomenon. But the central problem posed by H.R. 11764, to the DD program results indicated in the plans, is the one of potential loss of flexibility of response for the DD program. The gap filling mission of the current program tends to confirm the priorities of your bill, but the activities individually and by each state are considerably more variable than the national averages indicate and that H.R. 11764 would appear to allow.

When loss of flexibility in the gap filling mission is coupled with the apparent loss of systems advocacy options, the potential impact of the mandated services priorities and service funding distribution is severe. There is a real trade-off that can be made between the service-oriented approach of H.R. 11764 and the planning advocacy approach of the current program.

Perhaps that difference is really lost when the appropriations meet the authorizations. But in my opinion, the scale seems tipped enough on behalf of the current DD program concept to warrant continued support. The program will be a "buy" at twice the cost if it implements its stated activities.

Thank you.

[Testimony resumes on p. 360.]

[Dr. Henny's and Mr. Schpok's prepared statements follow:]

STATEMENT

RESPECTFULLY SUBMITTED
TO THE
HEALTH & ENVIRONMENT SUBCOMMITTEE
OF THE
HOUSE OF REPRESENTATIVES
INTERSTATE AND FOREIGN COMMERCE COMMITTEE

ON
HOUSE BILL H.R. 11764
DEVELOPMENTAL DISABILITIES ACT AMENDMENTS OF 1978

by

R. Lee Henney, Ph.D. and
Irwin L. Schpok

Directors, EMC Institute, Inc.
Philadelphia, Pennsylvania

April 5, 1978

STATEMENT

Mr. Rogers and members of the Subcommittee, we are pleased to be able to provide you with information which we believe to be highly relevant to your deliberations on H.R. 11764, "The Developmental Disabilities Act Amendments of 1978."

The substantive information of this discussion represents the effort of the Developmental Disabilities Planning Councils of the 54 states and territories currently participating in the program as well as our own accumulation of program and field experience in the past four years. It is our hope that this discussion and the written counterpart provided to you and your Committee members will enhance the development of renewed authority for what we have observed as a progressive, fruitful and unique demonstration in public social policy and program implementation under the present Developmental Disabilities Act.

In our estimate, the Developmental Disabilities Program is a program which is having an impact of increased services for its target population through comprehensive planning, influencing in accessing funds from many generic services and gap filling.

EMC Institute has been involved, over the last four years, with the development and implementation of the comprehensive planning system which is referred to as the Developmental Disabilities Evaluation and Information System (DDEIS). Mr. Schpok, who will discuss the results of the analysis of the FY '78 State Plans in a few minutes, has been the principle architect of DDEIS, its construction and implementation. My involvement with the Developmental Disabilities Program over the past four years has been primarily in the area of field activity and training, bringing a background of management training in the industrial setting to the developmental disabilities community. The EMC Institute staff members have worked in every state in the Union and participating territories in implementing the Comprehensive Planning System and also in providing management training for professional staff persons of DD State Planning Councils. Therefore, we feel that because of recent and continuing interface with the Developmental Disabilities Program we can present meaningful testimony for your deliberation.

When speaking about the Developmental Disabilities Act, it is very important to focus on the needs of the individuals with developmental disabilities. The Developmental Disabilities Act is unique legislation in that it provides legislation for an especially vulnerable population in our country. The developmentally disabled population is composed of individuals who are in need of a complex number of services, provided by a variety of service agencies, and these services are expected to be needed throughout the lifetime of the individuals.

The overall purpose of any legislative effort for the individuals with developmental disabilities should be to insure that these individuals have the services available when they are needed, have the continuum of services necessary for the enjoyment and realization of life goals, and are able to access the services at the time of need. The Developmental Disabilities Program as now implemented attempts to insure a complete service network for a continuum of lifetime of service and a strategy for identifying and rectifying deficits in the service network.

The present Developmental Disabilities Program provides for three promises to individuals with developmental disabilities. These three promises are:

- The needs of individuals with substantially handicapping developmental disabilities will be addressed by state service programs in a coordinated manner providing services in respect to the functional needs of the individuals.

- Consumers and service providers will meet and evaluate the service network, identifying service gaps and establishing priorities and strategies for filling the service gaps.

- The Developmental Disabilities Program contains significant dynamics in that it can influence service provider agencies to provide categorical service resources to bear on the lifelong needs of persons with developmental disabilities.

The present DD legislation provides, in the mandated State Planning Council, for a partnership of consumers and public and private service providers to deliberate and act on the service needs of persons with developmental disabilities at the state and national level. The program uses, as its major method of action, the coordination and utilization of categorical service programs and the authority of collective knowledge and experience for the benefit of the individuals with developmental disabilities.

The Developmental Disabilities Program, during its relatively short history, has demonstrated, as the State Plan analysis shows, its ability to access categorical services and obtain coordinated efforts for individuals with developmental disabilities among and between service providers. The program also has demonstrated its ability to access fiscal resources from a variety of categorical programs for its target population. The dedication, commitment and individual authority of State and National Council Members, staff professional, and administrating agency personnel has been and continues to be felt throughout the nation. The dynamics of the Developmental Disabilities Program will be further demonstrated as these hearings continue this day. There has been an observable impact on the services available, both in quantity and quality, for individuals with developmental disabilities, because of the implementation of the DD Program.

The cornerstones of the current Developmental Disabilities Program are the comprehensive planning, systems advocacy and service gap filling missions of PL 94-103. We would recommend that these missions not be lost with the enactment of H.R. 11764. We will review each of these missions, the status of state efforts based on the analysis of FY '78 State Plans and the projected impact of the relevant provisions of H.R. 11764.

Two major concerns which we have are that comprehensive planning remain a cornerstone of any new legislative enactment and that states retain the right for program priority selection and program determination. We feel that the Committee, through the introduction of H.R. 11764, has made significant improvements in the current Developmental Disabilities Program.

We believe comprehensive planning has become an integral part of the DD Program in achieving its primary mission and this tool should remain in place in any new legislative directive. States how have in place a comprehensive planning system which permits the Councils and administrative agencies to respond to gaps in the service network in relation to realities of the political and service activities at the state and local level. Even though the four priorities identified in H.R. 11764 are the priorities of over 50 percent of the states in FY '78 State Plans, it would be unfortunate to assume that all states and territories have the same service priorities. It would also impede the development of a continuum of services through strategic gap filling if the DD Act required specific priorities for all state service networks. The mandating of priorities would also dilute the dynamics of consumer/agency analysis at the Council level. Therefore, we would ask the Committee to carefully examine any priorities which it would mandate for the totality of the service network insuring that these were the total need and not average need as is shown in the State Plan analysis.

The second concern which we have is the 70/30 percent distribution of formula grant monies. Our concern is that if 70 percent of the monies are required for gap filling, it might, as historical evidence indicates, provide the replacement for categorical service dollars which can be accessed from existing programs for the benefit of individuals with developmental disabilities. Analysis of State Plans shows that Councils and administrative agencies have been able to tap other fiscal resources for every mission area. At present only 42 cents of every dollar spent for the DD Program missions is formula grant dollars. In our opinion the pro-rated distribution called for in H.R. 11764 would decrease the emphasis on accessing other categorical service programs for the needs of the substantially handicapped developmentally disabled, thereby setting up parallel services and denying the severely handicapped access to existing programs for the total population. We believe that the use of DD funds for identified gap filling is a correct one, but believe this to be the domain of the state and local Councils and administrative agency.

I now present Mr. Schpok who will briefly discuss the present state of the Developmental Disabilities Program as a result of an analysis of the State Plans and projected impact of H.R. 11764 in each of the program mission areas.

Mr. Chairman and members of the Committee, in my part of this presentation I wish to draw your attention to the missions of the current Developmental Disabilities Program, the planned activities of the states to fulfill these missions, and our opinion of the effects of H.R. 11764 on the State Developmental Disabilities Program. In these brief moments I will attempt to cover the three major operational missions of the DD Program: comprehensive planning, systems advocacy and service gap filling.

The Comprehensive Planning Mission

The comprehensive planning mandate and intent in P.L. 91-517 and amendments of P.L. 94-103 is clear: State Planning Councils are to develop and maintain a continuing and comprehensive plan for services to persons with developmental disabilities. The comprehensive State Plan is to include:

1. An assessment of the service needs of the developmental disabilities population.
2. A comprehensive review of the scope , extent and quality of current programs and services available to persons with developmental disabilities.

3. Identification of the gaps and barriers to providing needed services to persons with developmental disabilities.
4. Established goals, objectives and service and program strategies (design for implementation, funded or unfunded) to be addressed by service agencies and the State Planning Council.
5. Provision for proper and appropriate administrative structure for the DD Program including: State Planning Council and designated agency organization, responsibilities and staffing.
6. A review of the DD State Planning Council activities and accomplishments.

Comprehensive planning in the current DD Program is intended to be a key Council function. It is no less than the State Planning Council's public stand on how the service programs of the state are and should be addressing the service needs of the persons with developmental disabilities. It is intended to be the blueprint for coordination of categorical service programs and the strategies by which the Council will aid in filling gaps in services. It is to be a guide to the systems advocacy role of the State DD Program from principle to actual steps to be taken in each year of program operation.

Following the recommendation of a GAO report in FY 1974, the Developmental Disabilities Office (DDO) set in motion a long-range program to improve the capability and results of the planning activities of the Councils and simultaneously meet the national information needs for impact assessment of the program. (See Table 1). Basically, the three years of this DDO initiative beginning in FY 1975 included a feasibility test of the comprehensive planning system, followed by a nationwide voluntary test and then final modification and implementation of the planning guidelines.

To assess the results of the investment in the comprehensive planning system, it is important to know what the State Planning Councils were asked to do in FY 1977 planning guidelines. In accordance with the planning requirements of P.L. 91-517 and the amendments of P.L. 94-103, State Plans were to address a total of 275 information elements covering the six areas of comprehensive plan requirements I previously described. (See Table 2 below).

As the National Advisory Council Annual Evaluation Report (December 1977) states, the early response to the planning guidelines was mixed. At issue for the 10-12 states which were critical of the guidelines was the amount and scope of information being requested. For the 6-10 states which wrote in favor of the guidelines, the consistency of format and the flexibility allowed in the planning process were important factors.

TABLE 1
THE COMPREHENSIVE PLANNING MISSION

HISTORY

FY 1975 - DDO STRATEGY FOR PROGRAM IMPACT EVALUATION & ENHANCING PLANNING CAPACITY OF THE COUNCILS (3 years)

PHASE I - FEASIBILITY/EVALUATION STUDY

PHASE II - NATIONWIDE TEST OF PLANNING MODEL

PHASE III - IMPLEMENTATION OF PLANNING GUIDELINES AND TECHNICAL ASSISTANCE

FY 1975 - FEASIBILITY TEST RESULTS

EVENT
- RESEARCH MODEL OF STATE PLANNING PROCESS/GUIDE TESTED

RESULTS
- COMPREHENSIVE PLANNING POSSIBLE WITHIN PROGRAM ENVIRONMENT & RESOURCES
- PROGRAM IMPACT EVALUATION POSSIBLE USING TREND DATA FROM STATE PLANS

FY 1976 - NATIONWIDE TEST RESULTS

EVENTS
- REVISED MODEL STATE PLAN DEVELOPMENT GUIDE PREPARED
- FEDERAL GUIDE FOR IMPACT ASSESSMENT USING STATE PLAN INFORMATION DESIGNED
- ALL STATES TRAINED TO USE THE PLANNING MODEL
- PILOT TEST OF THE REVISED MODEL IN 4 STATES

RESULTS
- 30 STATES INDICATE USE OF MODEL FOR FY 1977 IF IN GUIDELINES FORM & ASSISTANCE AVAILABLE

FY 1977 - IMPLEMENTATION & TECHNICAL ASSISTANCE

EVENTS
- MODEL CONVERTED TO FEDERAL GUIDELINES
- INTRODUCED IN FEBRUARY 1977 THROUGH 10 REGIONAL MEETINGS
- ON SITE ASSISTANCE TO 44 STATES & TERRITORIES
- ALL STATES SUBMIT FY 1978 STATE PLANS IN FORMAT

TABLE 2
THE COMPREHENSIVE PLANNING MISSION

RESULTS FY 1978

WHAT STATES WERE ASKED TO DO:	#INFORMATION ELEMENTS
• SPECIFY SERVICE NEEDS OF DD POPULATION	46
• ASSESS SCOPE, EXTENT, QUALITY OF CURRENT SERVICE RESOURCES	56
• DETERMINE GAPS & BARRIERS	53
• SPECIFY GOALS, OBJECTIVES, PRIORITIES & DESIGNS FOR IMPLEMENTATION	36
• REVIEW COUNCIL OPERATIONS	28
• GIVE ADMINISTRATIVE ASSURANCES & DESCRIBE OPERATIONAL PROCEDURES	41
• SUMMARIZE	15
	275

Despite early controversy, the results of the effort of all states to fulfill their comprehensive planning mission are impressive (See Tables 3 and 4). First state planning management improved considerably over the three years: 70% of the State Plans for FY 1978 were submitted on or before the submission deadline as compared to 23% for FY 1975; and virtually all plans (95%) were submitted by the funding deadline for FY 1978 as compared to 53% for FY 1975.

Analysis of the FY 1978 State Plans completely dispels the claim that information is not available. Nationwide, the

TABLE 3
THE COMPREHENSIVE PLANNING MISSION
FY 1978 RESULTS

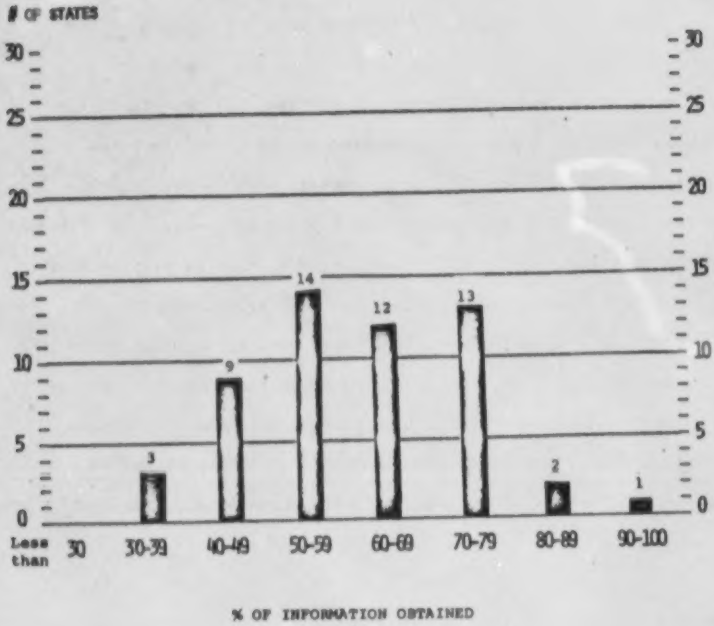
WHAT THE STATES ACHIEVED

- PLANNING MANAGEMENT
    - FOR FY 1975 23% OF THE PLANS WERE IN BY THE SUBMISSION DEADLINE
    - FOR FY 1978 70% OF THE PLANS WERE IN BY THE SUBMISSION DEADLINE (AUG. 1, 1978)
    - FOR FY 1975 53% OF THE PLANS WERE IN BY THE FUNDING DEADLINE
    - FOR FY 1978 95% OF THE PLANS WERE IN BY THE FUNDING DEADLINE (OCT. 1, 1978)
- RESPONSE TO REQUESTED INFORMATION
    - 30% (16) OF THE STATES REPORTED 70% OR MORE OF REQUESTED INFORMATION
    - 78% (42) OF THE STATES REPORTED 50% OR MORE OF REQUESTED INFORMATION
    - NATIONWIDE 61% OF THE REQUESTED INFORMATION WAS REPORTED
    - 48% (26) STATES SUBMITTED PLANS OF ADEQUATE AND OR BETTER QUALITY (EMCI SCALE)
    - 42% (23) STATES REPORTED 50% OR MORE OF THE INFORMATION AND WERE OF ADEQUATE OR BETTER QUALITY FOR THE ENTIRE PLAN
    - 79% (43) STATES OBTAINED 70% OR MORE OF THE INFORMATION AND WERE OF ADEQUATE OR BETTER QUALITY IN ONE OR MORE PARTS OF THE PLAN

54 State Plans contain 61% (168 of the 275 information elements) of the information requested. Sixteen (30%) states were able to obtain 70% or more of the information and 42 (78%) states reported

TABLE 4

AMOUNT OF REQUESTED INFORMATION
IN THE OVERALL STATE PLAN



50% or more of the information requested. Additionally, almost every state prepared some exemplary part of the plan. Forty-three (nearly 80%) states had 70% or more of the information requested and met the analysis objectives in at least one of the six areas of the State Plan.

From our experience, it is clear that the results of the comprehensive planning mission are based on the integration of the planning process into Council operations. In one state, the process resulted in the state agencies making a commitment to provide over 70 million dollars of generic service resources toward services for persons with developmental disabilities. These commitments (over twice the current national formula grant authorization) were made part of the generic service agency plans. In nearly all of the states Council members were involved in key planning decision processes including needs assessments, gap identification, and goal and objective development. In many states, Council members themselves were instrumental in the gathering of needed information. In our opinion, the comprehensive planning mission is being fulfilled.

The planning intent of H.R. 11764 is not clear. While there are references to "appropriate planning" in Sec. 101(6)(1) and (2) and further references in Sec. 133, comprehensive planning never quite reaches the mission status it now enjoys in P.L. 94-103. If the Committee wishes to capitalize on the current capability of the states to utilize the planning mission it can do so by legitimizing the functions of the State Plan and the Council's planning processes. In our opinion all that needs to be done is to reinstate the current planning mission in Sec. 101 (6) (1) and (2) (C) and add language to Sec. 133 (b)(2) similar to that listing the six areas of the State Plan we discussed earlier. Such a commitment would not require a loosening of the mandatory priorities and service funding distribution in your Bill although we believe such provisions to be unnecessarily restrictive. In Sec. 137(6)(3) the Council should have authority to review and comment on all State Plans affecting persons with developmental disabilities without qualification.

Mr. Chairman, the FY 1978 DD State Plans contain an abundance of information on the DD population characteristics and service needs, gaps to service provision and, most important, the actions of State DD Programs to be implemented in this year. Analysis of the planned activities has been organized into two other operational mission areas of the DD Program; systems advocacy and service gap filling.

The Systems Advocacy Mission

In the current DD Program, states address their systems advocacy missions through activities in five areas:

1. Protecting the legal and human rights of persons with developmental disabilities involving the operation of a Protection and Advocacy System.

2. Ensuring appropriate services to persons with developmental disabilities through individualized habilitation planning and public awareness and education action.
3. Promoting and effecting coordination of existing services and programs.
4. Promoting improvement in quality of services.
5. Monitoring and evaluating developmental disabilities service related programs of the state.

Analysis of the State Plans (excluding the Protection and Advocacy System) shows that State Planning Councils will be addressing themselves to all system advocacy mandates and options of the current law. Nearly 500 activities are planned nationwide to fulfill this mission of which 50% are dedicated to the coordination mandate, 23% to the promoting of appropriate services through public awareness and habilitation planning, and 20% to promoting improvement of service quality. Monitoring and evaluation activities are still lagging accounting for only 7% of the planned activities for the systems advocacy mission. (See Table 5).

Although the systems advocacy activities make up 60% of all reported activities (including service expansion activities) they account for only 27% of the costs reported for all activities. As might be expected the cost for systems advocacy activities will be borne by State DD Programs. However, there is evidence that other generic agencies will be paying more for the costs of

TABLE 5
THE SYSTEMS ADVOCACY MISSION (EXCLUDING P&A SYSTEM)
ANALYSIS OF PLANNED ACTIVITIES
FY 1978
(42 STATES REPORTING)

Area of Systems Advocacy	Total No.of Activities Reported	ACTIVITIES WITH COST DATA					
		No.of Activities	Total $	DDSA $	DDSA %	Average Cost/ Activity	$ Expansion Ratio
Ensuring appropriate service to persons with DD	116	74	$1,173,071	$ 949,242	81	$15,852	1:0.93
Promoting & Effective Coordination of existing service programs	248	226	$2,367,392	$1,628,389	69	$10,475	1:0.9
Promoting improvement of quality services	99	59	$ 891,674	$ 602,086	68	$15,113	1:1.1
Monitoring & Evaluation of DD related service programs	33	22	$1,563,307	$1,529,448	98	$71,059	1:0.8
All areas	496	381	$5,995,444	$4,709,165	79	$15,736	1:0.95

coordination activities than expected; every dollar of DD Program funds will bring nearly 30 cents of generic agency funds. Moreover, of 153 planned coordination activities 36% (55) are the responsibility of the generic service agencies themselves. The simple conclusion indicated is that the DD Program is gaining financial and implementation support in the area of its coordination mandate. A similar thread runs through the other systems advocacy activities particularly for implementation responsibility. Nearly 50% of all activities planned for the systems advocacy mission are assigned to generic service agencies for implementation.

Lest we make too light of this apparent achievement of the State DD Programs, think of it in this way. The national officials of vocational rehabilitation, social services, office of long-term care, maternal and child health services and education for the handicapped are sitting together, each pledging to the other 30 cents of their program dollar to ensure coordination of policy and service delivery in behalf of the DD population. Further, envision each agency director assuming the responsibility to implement this coordination.

H.R. 11764 pulls together the various aspects of the systems advocacy mission of the current DD Program through an exemplary job of organization. It is clear that the Protection and Advocacy System, promotion of legal and human rights, individualized habilitation planning, coordination and program monitoring and evaluation are central purposes of the bill. However, it appears from the features of Sec. 133 and 137 that the mandated and optional methods of achieving the systems advocacy missions will be narrowly focused on one or two service areas along with the program resources. If the Committee wishes to maintain the flexible and apparently fruitful response of the State Planning Councils to the bill's systems advocacy intent, serious consideration should be given to removing the mandated choice of a service focus and program fund distribution. Sec. 137 should also reiterate the purposes of the bill as State Planning Council responsibilities.

THE SERVICE GAP FILLING MISSION

Mr. Chairman, the service gap filling mission of the current DD Program is addressed by the State Planning Councils and administering agencies in four ways:

1. Developing community alternatives and sponsoring institutional reform (deinstitutionalization).
2. Developing prevention and early intervention programs.
3. Expanding existing services.
4. Demonstrating new service techniques.

Over 325 activities (see Table 6) in these four areas are described in FY 1978 State Plans. Most of the planned service gap filling activities are dedicated to expanding existing services (54%) and developing community alternatives and institutional reform (26%). Service gap filling activities of the DD Program

TABLE 6
THE SERVICE GAP FILLING MISSION
ANALYSIS OF PLANNED ACTIVITIES
FY 1978
(42 STATES REPORTING)

AREA OF SERVICE EXPANSION	TOTAL NO. OF ACTIVITIES REPORTED	ACTIVITIES WITH COST DATE					
		NO. OF ACTIVITIES	TOTAL $	DDSA $	DDSA %	AVERAGE ACTIVITY COST $	$ EXPANSION RATIO
DEVELOPING COMMUNITY ALTERNATIVES & SPONSORING INSTITUTIONAL REFORM (DEINSTITUTIONALIZATION)	84	79	$7,150,475	$3,778,478	53	$90,512	1:1.42
DEVELOPING PREVENTION & EARLY INTERVENTION PROGRAMS	36	30	$4,867,400	$ 278,000	6	$162,246	1:13.1
EXPANDING EXISTING SERVICES	178	160	$2,611,449	$1,879,345	72	$ 16,321	1:1.04
DEMONSTRATING NEW SERVICE TECHNIQUES	29	28	$1,593,679	$1,270,193	80	$ 54,917	1:0.94
ALL AREAS OF SERVICE EXPANSION	327	297	$16,223,003	$7,206,016	44	$ 54,623	1:1.69

will account for 73% of all reported activity costs. Our best estimate (based on very limited data in the State Plans) is that between 80 and 100 thousand persons with developmental disabilities will be served by these activities (see table 7). The average cost per person (again, based on limited data) estimated at about $617 nationwide.

DD Programs are demonstrating that they can access significant generic service resources in the service gap filling mission. In the areas of deinstitutionalization and prevention each DD Program dollar is bringing 42 cents and 13 dollars, respectively, from generic service resources. Institutional reform activities alone show return of 14 dollars to each DD Program dollar. Expanding existing services or demonstration of new techniques, as expected, do not "pay off" so handsomely.

Again, the conclusion seems evident: The DD Program is addressing its mandate and doing a respectable job nationwide of influencing the generic services to address the needs of persons with developmental disabilities.

The effects of H.R. 11764 mandated service priorities and fund distribution on current gap filling activities are not so evident. The current plan data seems to indicate less financial commitment from generic resources for existing service expansion. We can probably anticipate that a greater dedicated commitment of DD Program dollars to services will be followed by a reduction of

TABLE 7

NATIONAL PROJECTIONS OF THE* TOTAL NUMBER OF DEVELOPMENTALLY DISABLED TO BE SERVED FOR FY 1978

AREA OF SERVICE GAP FILLING RESPONSIBILITY	PROJECTED NUMBER OF DD TO BE SERVED BY THE 54 STATES AND TERRITORIES
COMMUNITY ALTERNATIVES	23,478
INSTITUTIONAL REFORM	5,932
PREVENTION	39,811
EXPANSION OF EXISTING SERVICES	8,933
DEVELOPMENT/DEMONSTRATION OF NEW SERVICE TECHNIQUES	9,138
TOTAL ALL PROGRAM AREAS	87,292

* Based on FY 1978 Design for Implementation data.

generic service dollars to the chosen areas. Other programs such as revenue sharing are demonstrating that federal dollars tend to divert, if not outright supplant, state and local commitments to other pressing areas.

But, the central problem posed by the current DD Program operation to the provisions of H.R. 11764 is the potential loss of flexibility of response for the DD Program. The gap filling mission of the current program tends to confirm the priorities of your bill, but the activities individually and by state are considerably more variable than national averages indicate and than H.R. 11764 would appear to allow. When loss of flexibility in the gap filling mission is coupled with the apparent loss of system advocacy options the potential impact of mandated service priorities and service funding distribution is severe, indeed.

There is a real trade-off between the service oriented approach of H.R. 11764 and the planning/advocacy approach of the current DD Program. The difference may be ultimately between authorization and appropriation. But, in my opinion, the scale seems tipped enough in behalf of the current concept to warrant continued support. The program will be a "buy" at twice the cost if it implements its stated activities.

Data and observations contributed by EMCI staff members:
Janet Elfring
Joan Geller
Sarah Grannis
Mary Rita Hanley
Lee Koenigsberg
Joy Ann Perisho
Marion Walsh
Typed by Phyllis Berlin

Mr. CARTER [presiding]. Mr. Wiegerink, it was the feeling of the chairman that I ask you to highlight your testimony, because we have a number of witnesses to appear before the committee. If you will highlight your presentation, we would appreciate it.

STATEMENT OF RONALD WIEGERINK, Ph. D.

Dr. WIEGERINK. Basically in my written testimony, I cover who are and the overview that we have of the country and essentially our work with DD councils [see p.—].

The DD councils and the staff across the Nation have accomplished much. In our estimation, they have been notably productive in five areas.

No. 1. Councils have been active in advocacy activities in behalf of persons with developmental disabilities and had been before the development of the protection and advocacy system. In fact, in five states, DD councils had statewide P. & A. activities as early as 1974. Councils provide a unique system advocacy approach to services for the developmentally disabled which complement the individual advocacy of P. & A. programs.

Point No. 2. Councils provide a forum for interagency planning and cooperation and override barriers imposed by agency competition. Councils have been active in developing interagency agreements and activities.

Point No. 3. DD councils have played a significant role in providing public awareness and public education. In addition to conducting public awareness campaigns, DD councils have brought hundreds of well trained specialists in the field of services for the developmentally disabled. These are individuals trained in planning, legal affairs, engineering, accounting, public relations, et cetera, who, through the program, have become involved and are key members in impacting our generic services on behalf of persons with developmental disabilities.

Point No. 4. DD councils have provided a base for developing quality assurance mechanisms. They have established grant review and audit systems; have evaluated planning and service operations; have developed case finding and case management operation; and have, from their overview of State activities, advocated the development of statewide client tracking and follow-along programs.

Finally and most importantly, from our point of view, DD councils have provided an access point for consumers and consumer representatives. With their one-third or more representation councils and their growing numbers among the staff to councils, consumers have been provided with access not only to information on the inner workings of human services, but also access to planning, monitoring and system advocacy. Consumer members are not passive participants. Most of the leadership positions are filled by consumer members. An example is Judy Brown, from your own State of Kentucky. We strongly recommend that DD councils be included in the extension of the DD program.

I notice that DD councils are specifically mentioned in H.R. 11764; we are concerned about the fact that they are not included in the Senate bill 2600. Paula will comment specificially on H.R. 11764.

STATEMENT OF PAULA BREEN HAMMER

Ms. Hammer. Dr. Carter, you and the members of the subcommittee have a positive track record of responding to the developmentally disabled and to the DD program generally. We thank you and the subcommittee for holding extension hearings on this topic and for being so open—and your staff—to accessibility. We support the essential elements of H.R. 11764 in continuing the DD program and maintaining a role and function for stated councils and also by increasing the authorization for the state councils and the protection and advocacy systems.

There are some changes contained in H.R. 11764 which are variously perceived by those of us in the field as either focusing a diffusive and elusive program concept, or as narrowing and confining State strategy to comprehensive planning and coordinating the broad range of services required by the developmentally disabled persons.

I would like to review several of the changes and focus on some key concerns that we have.

First of all, we are concerned about the 70/30 percent ratio of expenditures for services as opposed to the planning and advocacy function. This really goes to the head of the DD program concept. The question here is, is it in the interests of the bill to move the DD program into the business of providing direct services at the expense of the planning, coordination, monitoring and influencing fuctions that councils have performed?

Our recommendation on this point is that states would be allowed to continue to have the flexibility to spend the formula grant funds on services or on planning or on advocacy as they are necessary. I refer to the data that Dr. Boggs presented yesterday, which shows there is a wide range in how the states allocate their budgets. I think there is a need for flexibility in the States' determination of this issue. Many states spend 100 percent of their allocation in the influencing, planning and coordination function. It is important to retain the flexibility for those States to be able to do that.

We would recommend the deletion of the 70/30 ratio to allow maximum flexibility to the states. In fact, I would probably go so far as to say that any incentive or encouragement that might be given to councils to more more in the direction of planning and coordination and systems advocacy should be encouraged.

A second major point with regard to the legislation is the role of the State planning council in generating the State plan. We feel there is a need to clarify this language. The language in the current bill and in 11764 refers to the council's function to supervise the development of the state plan. Although that appears to be very clear language, by the time that gets through the HEW regulation process, there is considerable ambiguity about what that means. We would like to see that language clarified.

At a minimum, the council should establish the priorities for the plan and the council should have an active, not a passive, role in the planning process and should have final approval and disapproval.

I would like to see, also, some of the language in the findings and purposes section of the legislation. We are very comfortable with that portion of the finding language which states that the overall purpose of the bill is to assist states to serve developmentally disabled individuals through a system which coordinates, monitors and evaluates services.

We would suggest that the planning function be added to this portion as well. However, in section 101(2)(a), there is a call for a priority focue to the developmentally disabled person because his needs cannot be comprehensively covered or otherwise met in the education for all handicapped children act, the Rehabilitation Act of 1973 or other education and welfare programs.

The implications here are that there are many DD individuals whose needs are comprehensively met by such programs. We would like to make two points.

One, none of the categorical programs named serve comprehensive needs. A low-income disabled child may be entitled to health care under early period clinic screening diagnosis and treatment; income assistance under the supplemental income program; social services under title XX; and special education under Public Law 94–142.

Each program would require a separate individualized written prescriptive program. Unfortunately, there is little chance that the title XX social service worker will talk to the special education teacher, and there is the chance that the benefit packages really will be coordinated at the level of the individual child or developmentally disabled person. There is even less chance for a smooth transition for that person when eligibility status changes or when a child grows to the age when vocational rehabilitation or vocational education becomes a program option

We feel very strongly that the crosscutting mechanism that the DD council and the protection and advocacy system present, State program alternative, is extremely important in putting together a comprehensive benefit package for the individual whose needs are met and served by a number of catgorical service providers.

The second point related to this is that many disabled individuals who are eligible for and entitled to benefits under the categorical service program never make successful entry to the service delivery system. For example, we know that the participation rate of eligible disabled children in the income assistance program under SS is exceedingly low. There are many eligible children who are not receiving benefits under that program. Information barriers and the complexity of the process to even apply for those benefits is keeping many disabled individuals from receiving the proper entitlement under that program.

Having these statutes in the legislation in place is not sufficient. At the State level, some accessing of the facilitating mechanism is necessary. DD councils and the protection and advocacy systems fill this need.

In other instances, transportation barriers may be a problem to the adequate delivery of services. It is the DD council's gap filling missions that allow the legislation that we have on the books to be actually implemented at the State level in a way that is beneficial to developmentally disabled individuals. Enacting the legislation that we have, the civil rights of disabled individuals under section 504, 94–142, is the first step in insuring rights. But implementation at the State and local level requires the dogged persistence of advocacy organizations such as DD councils.

There are outreach functions to be performed. There is information function to be performed in making disabled individuals aware of what their rights are and how they can access their rights under the program. In many cases, individuals need specific help in making application for these benefits. State councils have made significant contribution in helping programs to better reach DD persons. It is very important that we retain this aspect of the DD program.

We now turn to the issue of setting priority areas. The priority areas highlighted in H.R. 11764 are important. In our view, every State will need some activity in these areas, whether planning, monitoring, system advocacy, or model programming.

Most DD councils have significant activities which could be clarified currently under these broad priority groups. Two points should be made.

First, there is an issue of what is the role of the DD council with regard to these priority areas. Is it a function of orchestrating existing services or a function of providing services under this categorical heading? Most of the priority services areas are the legitimate domains of existing service areas. These priority activities do not exist in a vacuum. State council responsibility should be viewed as that of orchestrating existing providers, not as setting up competing service programs. Councils should be encouraged to focus activities on priority areas but should be free to determine how best to impact these areas; whether that be through planning, influencing, advocacy, or model programing. We would argue for maximum flexibility at the State level.

Finally, I would like to call to the attention of the subcommittee the very real parallels between the struggle in the DD program as a comprehensive planning program with strong citizen participation to the struggles that this committee has observed over time with the health planning legislation.

I think many of the criticisms that have been brought forth with regard to the DD program are things that we have heard in the past about comprehensive health planning and about the new health services agency. We really look to this committee and the historical support of the comprehensive planning mission and the involvement of citizen participation to retain those issued in the DD program.

I will be happy to answer any questions you may have.

[Testing resumes on p. 376.]

[Dr. Wiegerink's and Ms. Hammer's prepared statement follows:]

HEARINGS ON HR 11764

SUBCOMMITTEE ON HEALTH AND ENVIRONMENT

HOUSE COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE

April, 1978

Presented By

Ron Wiegerink

Paula Breen Hammer

Developmental Disabilities Technical Assistance System

University of North Carolina

Chapel Hill, North Carolina

Mr. Chairman and members of the Committee -- Paula Hammer and I are pleased to be able to testify in support of the continuation of the Developmental Disabilities Program and the continuation of the Developmental Disabilities Councils and their significant role in improving human services for persons with developmental disabilities.

Ms. Hammer and I are from the Developmental Disabilities Technical Assistance System, a program of national significance funded by the Developmental Disabilities Office and located at the University of North Carolina at Chapel Hill. DD/TAS has provided technical assistance and training to our nation's Developmental Disabilities Councils since 1972 and is currently in its sixth and final year. During this time, we have interacted with Council members and personnel from every state and territory and personally provided on-site assistance in 40 states and two territories. We have conducted 109 orientation sessions for over 2,000 DD Council members and staff and have supplied consultation in the areas of organizational development, program planning and evaluation, public awareness, resource development, advocacy, deinstitutionalization planning and other areas of program development. This interaction has provided us with a unique overview of the functioning of our Councils across the nation over time. We have witnessed DD Councils' struggle to establish identity, organization, commitment, and to impact on the human service delivery system on behalf of the developmentally disabled. Despite the fact that DD Councils have had to contend initially with being foreign bodies to state government, to operate with ever-changing rules, regulations, and reporting formats, and to operate with yearly turnover of staff and membership, they have remained viable and functional. DD Councils in every state and territory can point to specific accomplishments unique to their state's human services. The fact that they exist and operate as outlined in Federal law and regulations is alone a notable accomplishment; the fact that they are often at the heart of planning, advocating, and monitoring services for the developmentally disabled is a significant feat.

We would like to comment briefly on DD Council functioning and then comment specifically on House Bill HR 11764.

DD Councils are very diverse in nature. In size, they have varied from six to 60 in membership with staffs from one to 38. Some meet monthly, some twice a year; most meet four times a year. Their placement in administrative agencies varies from lowly subdivisioned status in mental retardation and mental health agencies to highly visible status in human resources and Governor's planning agencies. To speak of Councils is to speak of the variety in states and territories, themselves.

Their singularity derives from their process of development from foreign objects thrust into ongoing state agencies to partners for change. Slowly they are achieving a match between their structure and function and the needs of their states in serving developmentally disabled persons. By last count, 20 Councils are operating under state legislative authority; the others by executive orders and budgetary action. Despite the constraints imposed by ever-growing state human service agencies, DD Councils are playing unique and needed roles in state government.

DD Councils and their staff across the nation have accomplished much -- in our estimation they have been notably productive in the following areas:

(1) Councils have been active in advocacy activities on behalf of persons with developmental disabilities and had been before the development of Protection and Advocacy Systems (P & A). In fact, five states' DD Councils funded statewide P & A activities as early as 1974. Councils provide a unique systems advocacy

approach to developing services for the developmentally disabled which compliments the individual advocacy of the P & A Program.

(2) Councils have provided a forum for interagency planning and cooperation that overrides barriers imposed by agency competition. Councils have been active in developing interagency agreements and activities.

(3) DD Councils have played a significant role in providing public awareness and public education. In addition to conducting public awareness campaigns, DD Councils have brought literally hundreds of well trained specialists into the field of services for persons with developmental disabilities. These are individuals trained in planning, legal affairs, engineering, accounting, public relations, etc. who through the DD program have become involved and are key figures in impacting on generic services on behalf of persons with developmental disabilities.

(4) DD Councils have provided a base for developing quality assurance mechanisms. They have established grant review and audit systems, have evaluated planning and service operations, have developed case finding and case management operations, and from their overview of state activities, have advocated the development of statewide client tracking and follow-along programs.

(5) Finally, and, perhaps most importantly, from our viewpoint, DD Councils have provided an access point for consumers and consumer representatives. With their one-third or more representation on

Councils and their growing numbers among the staff to Councils, consumers have been provided access not only to information on the inner workings of human services but also with access to planning, monitoring, and within systems advocacy. Consumer members are not passive participants; in fact, most of the leadership positions on DD Councils are filled by consumer members.

Thank you for the opportunity to testify in support of HR 11764. Paula Hammer will now specifically address our reaction to the bill as it stands.

SPECIFIC COMMENTS ON HR 11764

Mr. Chairman, you and the members of this subcommittee have a long and positive track record of responding to the needs of developmentally disabled people and supporting the DD program. We support the essential elements of HR 11764 which continues the DD program and maintains the role and function of State Planning Councils and increases authorization levels for the State Councils and the Protection and Advocacy Systems. Some changes contained in HR 11764 are variously perceived as either focusing a diffuse and elusive program concept or as narrowing and confining the state strategies of comprehensive planning and coordinating the broad range of human services required by developmentally disabled persons.

We will review these changes as they relate to the State DD Council role and function.

We have two major concerns in reviewing HR 11764.

I. Section 133(b)4. The 70 - 30 ratio of services: Planning and Advocacy.

Is it the intent of the bill to move the DD program more into the business of providing direct services at the expense of planning, coordination, monitoring, and accessing generic service resources? Carried to its logical conclusion such a move would lead to the development of yet another categorical service program. The decision making about allocation of funds among the various program functions should remain with state discretion. As noted by Elisabeth Boggs in a recent article (State Government, Autumn, 1977):

> That such options are helpful is illustrated by the shift in utilization. In the first year of the new act (fiscal 1971), states spent 14 percent of their formula funding on planning, 55 percent on services, 22 percent on construction, and 9 percent on administration; in 1977, the ratios were 19 percent, 72 percent, 1 percent, and 8 percent respectively. Of even greater significance is the wide variation among states in any one year, indicative that, indeed, mandating percentage allocations among such functions from the federal level based on preconceptions, however derived, can straightjacket the individual states.

II. Council Role in Generating the Plan (Section 137b).

With strengthened Council staffing required by PL 94-103 and increased competence of Council members, most Councils are totally capable of developing the State Plan.

A source of continuing confusion and some conflict is the ambiguity of the present statute regarding who writes the plan, who determines priorities, and who calls the shots.

A real administrative dilemma over division of responsibility and authority has arisen from the term "supervise the development of the State Plan." This language should be clarified. At the minimum the Council should establish the priorities for the Plan. The Council should have an active, not passive role, in the planning process and should have final approval - disapproval authority.

FINDINGS AND PURPOSES

We are very comfortable with that portion of the Findings and Purposes [Section 101(b)(1)] which states that the overall purpose of the bill is to assist states to serve developmentally disabled individuals "through a system which coordinates, monitors, and evaluates" services. We would suggest that the planning function should be added, however.

Section 101(2)(A) calls for priority focus to persons "whose needs cannot be comprehensively covered or otherwise met under the Education for All Handicapped Children Act, the Rehabilitation Act of 1973, or other health, education or welfare programs. The implication here is that there are many DD individuals whose needs are comprehensively met by such programs. We would make two points here:

(1) None of the categorical programs serves comprehensive needs. A low income disabled child may be entitled to health care under EPSDT, income assistance under SSI, social services under Title XX, and special education under PL 94-142. Each program requires a separate individualized written prescriptive program. Unfortunately, there is little chance that the Title XX social worker talks to the classroom teacher or that the package of benefits is truly coordinated. There is even less chance for smooth transition as eligibility status changes: for example, when the child reaches the age at which vocational rehabilitation or vocational education becomes a program option.

(2) Many disabled individuals who are eligible for and entitled to benefits under the categorical service programs never make successful entry to service delivery systems. For example, information barriers and the complexity of the eligibility process may account for the low enrollment of disabled children for SSI cash assistance. Transportation barriers may prevent those eligible for certain health services from ever benefitting.

Councils have made significant contributions to help generic programs better reach eligible DD persons: Massachusetts SSI Advocacy Center.

PRIORITY AREAS

The priority areas highlighted are important. In our view, every state would need some activity in these areas whether planning, monitoring, system advocacy or model programming. Most state DD Councils have significant activities which could be classified under these broad priority groupings.

Two points should be made:

(1) Orchestrate vs. Procedure Service

Most priority service areas are the legitimate domains of service agencies. These priority activities do not exist in a vacuum. State council responsibilities should be viewed as orchestration of of existing service providers not as setting up competing service programs.

(2) State Option

The proposed HR 11764 appears to give sufficient flexibility to states in selecting one or more "priority areas" for attention. Maximum flexibility should be maintained. In addition, states should be free to choose how to impact these service areas whether through planning, evaluating, coordinating, advocacy, model program support or a combination of strategies.

Mr. **Carter.** I am very much interested in the success of programs for which these funds are intended. Of course I want the planning that is necessary and the coordination that is necessary.

Yet, it does not amount to anything unless we have service to the people who have the disabilities.

I notice with interest that you just mentioned the flexibility at the State level. Just this morning I had a lady physician in my office who had been with the State department of health in Kentucky. She said as a result of this flexibility, the funds for epilepsy were off the track and lost their intended purpose.

I realize that different areas have different problems. I hope in all the planning you do, that instead of weaving a network of conflicting plans you could coordinate and streamline them, to use funds to train people, not just statisticians who know how to handle the mentally retarded.

I have seen some of those people; I have visited these places. Not as much as I should, but as much as I can. It is impossible to do all the things you want to, to see how these programs work, but I am going to devote all the time I can to this task.

As far as this funding is concerned—and it is not too much, I believe it was $30 million last year—I would agree that very little of it should be used for providing direct services. In fact, we have other methods of funding such as the "Little Schools of Hope" that we have for mentally retarded children. We need planning, but for goodness sake, don't tie us up in a tangle of planning so that we can't get services to the people who need them.

Mr. **Henney.** I think Dr. Boggs' presentation yesterday, which had the chart on how moneys were spent, showed that an average of 30 percent of the $30 million spent by the councils over last year or planned this year was for planning, and 70 percent was for services and administration.

However, the problem is that there is no one State; and we come again to legislative mandate by averages. Let me assure you that all of the councils are interested in the coordination of services, but in our categorization of social programing that we do by legislation and our population which is vulnerable and needs a continuum of life services, if we do not have the coordination of which you speak and if we do not have somebody looking at and interfacing with the various agencies in some directed way, these gaps cannot be filled and we get people served very well at one age and not at all at another age.

Mr. **Carter.** Still we don't want the mountain to labor and bring forth a mouse.

Dr. **Henney.** That is quite true.

Mr. **Carter.** I think I have made my point, Mr. Chairman.

Mr. **Rogers.** Thank you, Dr. Carter.

Of course, all of us recognize the importance of planning, but once a comprehensive plan has been formulated, do we need to do that every year?

Dr. **Henney.** It would seem a simple update. As you were saying yesterday, a 3-year planning cycle might be sufficient.

Mr. Rogers. Of course if something comes up, it could be brought into a plan.

Dr. Henney. Absolutely. The councils are to the place now where data have become significant in their utilization and preparation for not only services but influencing, impacting on the service agency ad also impacting on significant legislation. Councils are now being able to use the comprehensive plan.

Comprehensive planning is only a tool, and the tool is only as good as it is honed and sharpened. So consequently, a 3-year cycle, as you suggested yesterday.

Dr. Wiegerink. There are many other important activities besides the comprehensive plan that councils are engaged in; the advocacy activities, influencing activities, developing new systems, and so on.

Mr. Carter. That is one of the things he has said. But as I interpreted what he has said about advocacy, he really didn't get down to its root purpose which is protection of the rights of these people.

Now he went on about teaching them. You shouldn't teach these people too much about legalistics and things like that, but you should protect them, if you are to be an effective advocate for them.

Mr. Weigerink. The DD councils can serve as a systems advocacy program to influence other generic programs and other categorical programs in terms of the developmentally disabled. That is a unique function they have that no other organization plays at this point. I am concerned that the bill as stated now, because of the emphasis on priorities and on the 70–30, will at some point produce another categorical DD program, service program.

While there is a tremendous need for services for the developmentally disabled, I think that the primary role that councils can play is one of accessing other generic services and other categorical services on behalf of the developmentally disabled. That is why the planning, coordinating, influencing, impacting role of councils is very important and that a 70–30 distribution for some States is not adequate to do that.

Mr. Carter. Mr. Chairman.

Mr. Rogers. Yes.

Mr. Carter. That makes very good listening, but it was the very way that funds for epilepsy lost their way to the epileptic and didn't get there.

Ms. Hammer. Mr. Chairman, the next panel that is coming will be able to give you some very specific examples of action-oriented advocacy activities that have helped individuals get services from generic programs at the State level.

One example from Massachusetts. In 1976, Massachusetts set up a program to alert the families of disabled individuals to their eligibility for services under social security supplemental income, income assistance and automatic medicaid coverage that accompanies that in the State of Massachusetts.

The DD council in Massachusetts sponsored a group to do an outreach, blitz campaign; 2 weeks, heavy media coverage. In 2 weeks, 300 families in the Boston area were enrolled in the program; 300 families of severely disabled individuals who said they did not know about the SSI program prior to that media campaign.

The SSI program is 4 years old. It had been in operation for 2 years. The Social Security Administration had not done good outreach for children under SSI. The DD program recognized that need and did the outreach that was necessary and got those individuals enrolled in this program.

These are the kinds of things we are talking about that, in the abstract, sounds very bureaucratic; plans and coordination.

Mr. CARTER. Absolutely. You have the "bureaucratese" down pat. I never heard so much in all my life, absolutely.

Mr. HAMMER. I think the next panel will be able to give you that kind of action example.

Mr. CARTER. I would like to see that.

Mr. SCHPOK. Mr. Chairman, I wonder if I could respond to your question about yearly planning.

Mr. ROGERS. Yes.

Mr. SCHPOK. If there is a service orientation of the bill, then a 3-year cycle clearly would be adequate for setting the goals in the service area. However, all the other programs which the DD council has a mandate to look at have one-year planning cycles.

If indeed they are shifting away from their previous commitments to this population, if their planning cycle for DD programs is not covering, looking at those plans and seeing the shifts and where they should be influencing, they will be behind in information on the major categorical plans.

So, the tradeoff I see, if it is influencing that the council has to do, then there is indeed a need for updating a good deal of information about what is going on in the generic services.

For the service part of the plan, it may be well just to hold the cycle to 3 years.

Mr. ROGERS. I would think any specific need could be handled on a yearly basis and still have a 3-year cycle on the overall comprehensive plan.

Mr. SCHPOK. Provided the process is in place for the councils to make yearly review and update where they see critical areas.

Mr. ROGERS. Isn't that part of their function?

Mr. SCHPOK. Yes.

Mr. ROGERS. Do you think the Council should have a major role in planning, rather than the State agency?

Mr. SCHPOK. Yes.

Dr. HENNEY. Yes.

Mr. ROGERS. All of you agree with that?

Dr. WIEGERINK. Yes.

Mr. ROGERS. Thank you very much. We appreciate your testimony today. I am grateful for your presentation.

The next panel will be Dr. James Watson, president of the National Conference on Developmental Disabilties, former chairman of the Oregon Developmental Disabilties Council; Mr. Roy Bruninghaus, director of the State Council on Development Disabilities; Mr. Artis A. Zody, chairman of the Montana State DD Council; Mr. Cordell Brown, chairman of the Ohio Developmental Disability Council; and Ms. Zebe Chesnut, executive director of the Georgia Council on Developmental Disabilities.

Mr. ROGERS. We are pleased to have you here.

Mr. Preyer wishes me to state he is sorry he cannot be here to greet you. He is on official business. So we welcome each of you. If you would help the committee on the time element, it will be appreciated. Your statement will be made part of the record in full.

You may proceed.

STATEMENTS OF JAMES MACDONALD WATSON, M.D., PRESIDENT, NATIONAL CONFERENCE ON DEVELOPMENTAL DISABILITIES; D. CORDELL BROWN, CHAIRPERSON, OHIO DEVELOPMENTAL DISABILITIES COUNCIL; ARTIS A. ZODY, CHAIRMAN, MONTANA STATE DEVELOPMENTAL DISABILITIES PLANNING AND ADVISORY COUNCIL; ZEBE CHESNUT, EXECUTIVE DIRECTOR, GEORGIA STATE PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES; AND ROY V. BRUNINGHAUS, EXECUTIVE DIRECTOR, NORTH CAROLINA COUNCIL ON DEVELOPMENTAL DISABILITIES, ACCOMPANIED BY JANE SMITH, ASSISTANT DIRECTOR

Dr. WATSON. I am Dr. Watson. I am also a physician, Dr. Carter. I also happen to be president-elect of the Epilepsy Foundation, and I would like to talk to you about Kentucky's problem. Maybe we can do something about it.

I carry a clipping with me which I must read to you, sir. It comes from a recent issue of Science. It says:

> It is not much of an exaggeration to suggest that had the present bureaucratic structure for control of research by legislation and regulation be in operation when polio research was in its hey-day, we might today have a compact, efficient, computer-operated portable iron lung rather than two vaccines.

I am on your side when it comes to the bureaucracy. This group is, in fact, a consumer group. The State councils which you have heard described to you are in fact the primary consumers of Federal policy. They then are those who attempt to deliver at State levels the developmental disabilities policies.

We happen to have a national organization, a "national conference", which is generated out of the obvious need for us to get our act together, if it is possible, in response to that and enable us to disperse our views 56 different ways in some rational fashion.

It happens, coincidentally enough, our national meeting has proceeded for the past 2 days in the city. Yesterday, we were privileged to have Miss Nelson come and talk to us about what your committee and its philosophies were currently at that time. She was equally gracious in offering us an opportunity to appear before you. We would have bent every effort to do so, anyway, but we are in town, so here we are.

As a matter of fact, I have a panel whose presentations represent one large State with lots of "dough," in my sense; one state with lots of geography and very little money; one State in the middle; and then Mr. Bruninghaus at the end. North Carolina, I am not sure how to typify. I will let him typify it for us.

Mr. BRUNINGHAUS. We have the basketball teams.

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Mr. CARTER. I thought Kentucky had the basketball team.

Mr. ROGERS. Today they do.

Mr. CARTER. No. 1.

Dr. WATSON. I would like to apologize for Mr. Bruninghaus' ill-timed remarks.

Dr. WATSON. However, if you can give us that fellow Givens, the Trail Blazers would like to have him.

Mr. CARTER. We are going to keep the "Goose". He graduates this year.

Dr. WATSON. I would like to introduce to you the chairman of the Ohio Developmental Disabilities Council, who is himself a consumer in the true sense. He also is the newly elected vice president of our national organization, Mr. Cordell Brown.

[Dr. Watson's prepared statement follows:]

Introductory remarks, James MacDonald Watson, President,
National Conference on Developmental Disabilities,

April 5, 1978

The organization of the State Councils, the National Conference on Developmental Disabilities (NCDD) has been responsible for a good portion of the overall progress made in the field of "DD" in the past several years; progress not at all uniform and not at all to the liking of our more severe critics. Presently some 75% of the councils ar actively participating in the organization which has developed from the insights of a few strong council people who recognized that a multi-state, multi-regional situation existed which the legislation did not address, and determined that a coherent and unified approach to various problems could come from a National group omly.

NCDD is non-statutory, of course, and is comprised of three delegates from each state or territorial council. It has had one if not two National meetings each year since its inception, and with the guidance of a thoughtfully chosen executive committee has produced effective contributions in regulation development and clarification, renewal legislation, minimally-funded and/or rural state problems, and coordination of an overwhelming whealth of "technical assistance for state councils. The executive committee has maintained a very close liaison with the National Advisory Council, and we have represented the councils as members of the Task Force on Definition, and in the advisory council of the Federal Programs Information and Assistance Project (FIPIAP), a national significance project.

The present mission for the Conference is to shepherd closely the new legislation that must develop, with plans for a winter meeting to look at "evaluation".

NCDD is supported entirely by voluntary support from its individual councils, but recently incorporated in the District to allow it to seek grants and contracts for specific functions, being scrupulous to avoid using state formula grant monies for "lobbying". We are attempting to establish a formal membership "dues" protocol with pro-rated levies for each council, but this is not yet developed.

I am happy to introduce to you four panelists, representing all of our "classes" of membership: chair, staff, and consumer. I thank you and your staff for your solicitation of our views, and assure you that we and the committee share a single goal.

STATEMENT OF D. CORDELL BROWN

Mr. Brown. Thank you, Mr. Chairman.

Mr. Rogers and fellow members, instead of reading my testimony [see p. 383], which might be redundant, I think one of the concerns that Mr. Carter has, I can address myself directly to. That is, the impact that the councils have had on service over the past several years.

I am not only acting chairperson of the Ohio council; they no longer allow me to be classed as a consumer because I also am director of an agency that provides three major services. One is residential facilities for the severely physically handicapped persons; basically cerebral palsy.

Second, we operate a recreational progam for a whole spectra of developmentally disabled.

Third, we do provide a travel program.

Because of this, I am no longer a consumer. I only shake like one.

Dr. Watson. I wish I could shake like that.

Mr. Brown. In 1971 and 1972, when the DD Act was basically getting its council together and were more into the direct service providing program of giving grants, our organization saw the tremendous need to provide residential alternatives. At that point in time, knowing nothing of DD or even the term, one of my staff members came back from a trip in southern Ohio and said, "Hey, Cordell, here is a way we might get some seed money to start our residential program," where subsequently we did.

I strongly support reenactment and extending Public Law 94–103, based on three reasons.

No. 1, in my estimation, it is the only mechanism now in existence where I, as a consumer, also a developmentally disabled person and a service provider, can walk up to an agency representative such as a director of mental retardation in Ohio and, on an equal basis, sit down and talk about the problems of my people. This is what the councils are able to achieve on an equalization and not a role-playing bureaucratic basis. There is no other mechanism for that.

No. 2, it is the pilot program that has put tax dollars into the three areas. Prior to Public Law 94–103, there were no tax dollars virtually being tapped. CP, epilepsy, and autism; of course we had a good movement prior to the enactment for the mentally retarded, but I think it has been enhanced, and one of the enhancements is now known as the deinstitutionalization, and we could spend all morning on that program.

No. 3, I feel that a lot of the council concepts would give parents and consumers a very detrimental setback. The DD legislation is just now getting its total act together. Extension of the bill for 2 years will give everyone in our population more hope, and I am sure the concerned citizens and concerned professionals can bring to a very special and forgotten population hope for the future.

Thank you.

[Mr. Brown's prepared statement follows:]

April 4, 1978

Testimony on HR 11764
Rev. D. Cordell Brown, Chairperson
Ohio Developmental Disabilities Planning Counsel

Introduction

Mr. Rogers and Members of the Sub-committee on Health and the Environment.

My name is Rev. Cordell Brown, acting Chairperson of the Ohio Developmental Disabilities Planning Council; also director of a community residential facility for the severely handicapped in Warsaw, Ohio.

The Ohio Developmental Disabilities Council feels that PL 94-103 is an excellent piece of legislation and should be extended two more years. The present Act provides for unique forum for change with one third of its members representing state agencies, one third consumer representation and one third consisting of service providers. There are twenty one members on Ohio [illegible] Council.

Some of the programs for which the Ohio Developmental Disabilities Council has been primarily responsible are:

SENATE BILL 71 - Zoning legislation to encourage the development of group homes in Ohio.

EARLY INTERVENTION PROGRAMS - Three programs are presently in operation in Ohio. These programs teach parents how to properly care for their handicapped child. Also provides information on available services.

MENTAL RETARDATION PREVENTION PROGRAM - Under the program guidelines, each child will be given a blood test at birth to try to determine the presence of a condition which could result in mental retardation or other developmental disabilities.

DE-INSTITUTIONALIZATION PROJECTS - Based on community arrangements - such as apartment training for clients released from the institutions into the community.

STUDENT PUBLIC AWARENESS - These programs provide training and education to teachers as well as students in the causes of disabilites. Our feeling is that we can develop positive attitudes at a younger age.

The list is approximately 21 projects long, including projects of National significance at (Neisonger Center). A "University Affiliated Facility" in Columbus, Ohio. Further information on other projects are available upon request.

The Ohio Developmental Disabilities Planning Council opposes any effort to consolidate regional discretionary monies under this program to the Developmental Disabilities Office. It doesn't allow for local and regional input into the expenditures of those funds. The HEW Region V office has efficiently and effectively utilized these funds over the past years to serve Region V States with a "maximum" of State input.

We also support HR 11764 with minor changes.

1. Grant funds should not be limited to specific priorities. as it limits the flexibility of Council's to plan for their unique needs.

2. Eliminate the 70% Rule. It will dilute our efforts , particularily in small allocation states to develop a state plan which will do more than describe "what is" in a state but which will also adequately assess and recommend "what could and should be and which will allow the state the opportunity to maximize the effective allocation of resources for services to persons who are developmentally disabled.

CONCLUSION

One thing that I feel we should remember is that the Councils' unique organization provides a mechanism by which consumers, non profit providers, and State agencies can work together to provide the quality services that persons who are developmentally disabled deserve.

Mr. **Rogers**. Thank you, Mr. Brown, for an excellent statement and for a very helpful one. We are grateful for your being here.

Dr. **Watson**. I wonder if I can call on Mr. Zody, former State senator from Montana. He represents their council as its chairman. He also represents what we really have not talked too much about in council membership, and that is most of us are in fact volunteers. That can't be stressed enough. Artis drives 425 miles from his home to his office. About all he sees are jackrabbits, and I don't know what else. But tell us about it from Montana.

Mr. **Rogers**. Big sky, anyhow.

STATEMENT OF ARTIS A. ZODY

Mr. **Zody**. First, let me say I am pleased to have a chance to appear before you. I am not going to take too much of your time, and I am not going to go into my written testimony [see p. 387]. You have it before you. Let me bring you a bit of background, if I might.

When you say a person is a professional, you immediately assume that he has a number of degrees. That seems to be the normalization. I don't have any degrees in that sense, but I do consider myself a professional. The reason I consider myself a professional is because 22 years ago tonight, I became the parent of a retarded child. Twenty-three years of dealing with retardation in its many aspects I think does entitle me to say I have some professionalism. I think I have a certain degree, if tenure means anything, a certain degree of professionalism from the standpoint of council membership because I started serving on the council when they first came into being in 1971. I have served continuously since then and been chairman for a number of years.

I have seen our council, gentlemen, grow from a strictly grant giving council who took the dollars they had—meager as they are because we are a minimal allotment State—and set aside more of that into a granting area. I have seen us grow from that to a council that is really after planning in a total aspect and our primary concern, the very premise from which everything springs, is the fact that the end result of that is service to that son of mine, that daughter of yours with cerebral palsy or whoever it may be.

I have seen those councils grow. I have seen them become sophisticated.

There has been a tremendous turnover in council membership. As has been said, we are volunteer people. We don't do it for the money because there is no money in it. We do it because we have a concern. We are strictly volunteers.

As Jim says, I just happened to be a bit further away from my staff office, by 475 miles, then perhaps some of the others are, because there are some who are relatively close. Nevertheless, it means, when I go to the council meeting, a day on the road and a day back. No one twisted my arm to become involved. I recognize that. I am involved and I will probably stay involved as long as I can because I have a deep concern.

I would like very much to touch briefly on the roles of the council's influence, impacting, monitoring, and evaluation. If I may, I would like to dwell specifically on impact. I think that is where the ball game is.

I think impacting, causing things to happen, getting people involved, changing attitudes and minds, getting agencies to coordinate and cooperate, is not enough. That is the ball game. That is the thing that generates dollars and generates services. That uses agencies and and bucks that are already there in the best use of those bucks.

Let me give you a good example, and let you use your imagination. In a minimum allotment State, $150,000 is such a minimum amount that if you were to put it all into services it still would not do the job. I think at this point I need to make one comment. I know dollars are impotrant. Without dollars we can't accomplish things. You know that; I know that. We also have to remember and not fall into the trap of thinking if we had all the money in the world it would solve all the problems. It never will, and it can't. I think you recognize that as well.

Imagine for a moment you are standing on a rather steep hillside, a rock-strewn hillside. As you are standing there surveying the scene, you happen to look down and you see before you a very small branch of a tree. You take that and you pry a rock loose at your feet. As that rock goes down the hillside, it hits some more, and they in turn hit some more. Finally, when the dust is settled and the air has cleared, you have changed the landscape.

Basically, that is exactly what the councils are doing. They are changing the landscape. They have changed the landscape. They will continue to change the landscape. If you put us in a bind, in a situatio that we cannot use those dollars we have for just exactly those kinds of things and tie us down too stringently in the service area—and I understand, Mr. Carter, where you are coming from; that is the ultimate result—but if we can impact on people and if we can change those so that people in turn can talk to other people, you get better cooperation, and that in the end will result in better services. That is basically my concern.

I am very thankful that deinstitutionalization is here. By the way, I would like to speak to that for a moment. I know how it works.

My son was in an institution 475 miles from home. He is now in a community group 50 miles from home. He is happy, and we are happy. The deinstitutionalization we have to be careful of; that it does not become a numbers game, and instead of creating better arrangements we merely set up many institutions across the States.

I have been on the council for all these years. I have seen the council membership. Let me remind you again that one-third of that membership is made up of people who are either consumers or parents of consumers. The end result of that concern is service to those people that they are representing.

Thank you.

[Mr. Zody's prepared statement follows:]

STATEMENT OF TESTIMONY

BEFORE THE

HEALTH AND ENVIRONMENT SUBCOMMITTEE

ON HR 11764 DEVELOPMENTAL DISABILITIES

AMENDMENTS OF 1978

Respectfully submitted by:

Artis A. Zody
Chairman
Montana State Developmental
Disabilities Council

April 5, 1978

Mr. Chairman, members of the subcommittee, my name is Artis A. Zody. I am Chairman of the Montana State Developmental Disabilities Planning and Advisory Council. I have served as Chairman of the Council since 1972 and am one of the three members of the Council who have served since 1971.

Mr. Chairman, and members of the subcommittee, I am pleased to have this opportunity to testify on HR 11764.

I am the father of a developmentally disabled son, who is presently residing in a group home for developmentally disabled persons. My son is 50 miles away from his home, where-as, he was previously in a State Institution located 475 miles away. Needless to say, he is happy at being closer to home, and so are his parents.

My purpose in providing this background is to give you an insight into what can be accomplished through deinstitutionalization.

However, deinstitutionalization does not happen over night, and in our State, came about through the committment of Governor Thomas Judge and the Legislature as a result of the advocacy role of the State Developmental Disabilities Council and others concerned with Developmentally Disabled citizens.

The role of the State Council, as mandated by the present legislation and as retained in HR 11764 is one of influencing, impacting, monitoring, and evaluating.

There is no excuse for having any legislation on the books that is not committed in total to serving the Developmentally Disabled in a way that gives them the greatest possible access to all of the opportunities for the pursuit of happiness and fulfillment that you and I enjoy as citizens of this Nation.

I feel that HR 11764 does provide the Developmentally Disabled this opportunity.

Mr. Chairman, and members of the subcommittee, you and I are well aware, that in many instances, these developmentally disabled persons cannot act and speak for themselves. They must have, and are indeed entitled to have, a spokesman and that is where the State Council can have a strong voice.

Lest I leave the impression, Mr. Chairman, and members of the subcommittee, that Developmental Disabilities State Councils are not prone to mistakes of judgment, sometimes critically short of adequate fore-sight and subject to all of the shortcomings that afflict most of us, let me assure you, they are! HR 11764 retains the Council structure and that is one of its good features.

There is however, contained in HR 1176[illegible], a feature which does concern me if State Councils are to be effective in their advocacy, planning, impacting, and influencing role, and that is the 70 per cent requirement into the "priority services".

In a minimum allotment State such as Montana, even if the **entire** $150,000 were put into services, it would really have very little impact on services to Developmentally Disabled persons. Councils cannot be called upon to provide continuing funding, even if we had three to four times this amount. The impact would still be minimal in terms of need.

One of the things that I have observed over the years as a Council member, is the tendancy of grant recipients not to take adequate steps to assure that having once established a service, State funding will follow and the service will continue. What happens so many times, is that the grant recipients will return again and again for further grants.

The solution in my opinion is for the State Council to be very actively involved in assisting those requesting the grant in assuring the following:

a. Is the project or program one that is a new service and does not duplicate an existing service.

b. Has every effort been made to determine whether or not an agency or agencies should be providing this service or program as mandated by State or Federal Law.

c. Has every effort been made to assure that after having initiated the service or program, via the grant, that there will be funding to assure its continuation.

We have enough money, if used this way, to do the job at least adequately. But the Councils' real impact is how it influences the State and that is hard to measure.

There is no way you can measure in dollars and cents or otherwise, what is the value, or what the impact will be of having changed a

Legislator's point of view, or of convincing a Department Director or a Bureau Chief that the client will be better served in another way.

How do you measure the effect of having been responsible for gathering under one roof the people from various agencies to talk about and plan together how to help the developmentally disabled persons receive those same State services that you and I enjoy? You cannot when you base your evaluation on the numbers of persons served with Developmental Disabilities dollars. The evaluation should coincide with the Legislative mandate to plan, influence, monitor, and evaluate.

Mr. Chairman, members of the subcommittee, I am simply trying to point out the necessity of allocating State Councils the greatest flexibility possible to carry out their mandate as outlined in HR 11764 and as a result the beneficiary will be the Developmentally Disabled persons about which you and I are concerned.

I could continue on at some length as to why I personally feel that use of State Councils is an effective way to bring about change that will be advantageous for developmentally disabled persons. Remember that a requirement of Council structure is the membership of consumers and consumer representatives and therein lies the voice of those closest to those, who for a reason I know not, have been chosen to be very special people!

Thank you.

Mr. **Rogers**. Thank you very much for an excellent statement.

Dr. **Watson**. Mr. Chaiman, we have with us two representatives of the planning component of DD, its membership. They happen to be the planners of two States who have singularly successful programs, in our view, and I would like to introduce to you first Ms. Zebe Chesnut, director of the Georgia Planning Council.

STATEMENT OF ZEBE CHESNUT

Ms. **Chesnut**. If you allow me, I will forego my written testimony and attempt to answer some questions you have asked.

The membership of the DD council in Georgia is made up of 36 people. We are located in the Office of the Commissioner of the Department of Human Resources. I want to build on what Mr. Zody said in using his analogy of the rock that begins a landslide and relate some specific examples of how DDSA money in Georgia is the rock that may often cause this landslide.

First, I impress upon you the fact that planning in the sense that we use it in Georgia includes more than planning, numbers, and data. When we say planning—and 33 percent of our money and sometimes more is used for planning—we are talking about activities that are not direct service related; activities that are influencing, monitoring, resource mobilization, and coordination. So when we say planning in Georgia we do not—and I think many DD councils do not—speak of just data and number but of these activities that are not direct services. Now, where does the money go?

In the past year the Georgia council has influenced the Governor to require a comprehensive master plan for special education as a contingency for signing the Public Law 94–142 implementation plan in Georgia. They have influenced the Governor to request a joint agreement between the Department of Human Resources and the Department of Education. This agreement is in writing. The Department of Human Resources and the Department of Education have agreed on who is responsible for what in serving the handicapped children under Public Law 94–142. They have influenced the Governor's office to establish a Joint Committee of the Department of Human Resources and the State Department of Education so these two departments could work together in a coordinated approach to deal with the common problems of developmentally disabled and handicapped children as many enter the public schools.

The council has played a key role in the passage of State legislation and appropriations affecting the handicapped in Georgia, including a fair employment practices act that prohibits hiring discrimination in State government against handicapped persons and a mandate that special education training be required for regular classroom teachers, for school administrators, and for school counselors.

The Georgia council has been active in the field of prevention through endorsement of State dollars to support early screening for genetic disorders. This year we had over 350 new special education teachers funded with State appropriations, along with additional transportation to support those, to assist in the implementation of Public Law 94–142.

In the area of resource mobilization and coordination, the council provides direct technical assistance to assist communities in accessing additional resources. For example, a $30,000 contract with DDSA dollars has assisted in generating over $3 million in the area of HUD funding for the State of Georgia and over $500,000 in SBA loans and local moneys to provide better, more appropriate training facilities for the developmentally disabled. To me, that is a little rock beginning the landslide that ended with a rather large mountain.

We have sponsored numerous demonstration projects in the area of direct service which when proven effective were transferred for financial support to a state responsibility.

There are two service programs you might be tremendously interested in in terms of specifically documenting the most effective and appropriate way to use the DDSA dollars for services. States often cannot afford to take the risk involved in demonstrating a new idea. State dollars are by necessity used on programs that have been proven effective. I refer to something in Georgia called the Gleaner project, in which with $35,000 10 men, most out of institutions, whose IQ's were between 19 and 38, the average IQ being 32.3, were returned to the community and given jobs in the Gleaners program. Half the men had been institutionalized for periods ranging from 10 to 28 years, and most had never held a job.

The attempt was to prove the economic feasibility and appropriateness of farm-related labor for those people with developmental disabilities who were from a rural community and who wished to participate in the program.

That is a very difficult project for some of the administrative agencies to do because of the redtape and bookkeeping involved in paying participants the minimum wage and establishing a system so that these persons with a developmental disability would have incentives to make more money. Several persons made over $100 a week; these same people had been costing the state $17,000 per year in the institution. Most important these people regained or in some instances experienced for the first time a feeling of self worth and dignity.

As a result of the fact that we did fund this as a new demonstration, the Division of Mental Health and Mental Retardation in Georgia found this to be a cost-effective program and worthy of adopting in other areas of the State. Community program personnel will be trained to add this component to already existing programs. Cost will be minimal.

Another example: The DD Council in Georgia felt with the mandate for deinstitutionalization, that some person needed to be responsible in each of the institutions for the people who were being returned to communities. Council wanted to insure that the services they got were more appropriate than those of the institutions.

We funded eight positions and attached it to each of eight institutions to do a management coordination activity for the persons who would be deinstitutionalized. Before a year was over, the State legislature in Georgia funded 23 of these positions, returning the

DD Council funds to us and letting us then use that money to generate additional money or activities in other areas.

In terms of the DD Council and our authority in advocacy, we see our responsibility as a global, statewide systems advocacy. We support and understand the need for individual advocacy and protection which we have in the present DD law under the P. & A. system.

Georgia got close to $70,000 to begin their P. & A. system. The DD Council did not feel that was quite enough, so we awarded the P. & A. system $100,000 of our State grant. We also gave them our support in going to the State legislature and asking the State to supplant those Federal DDSA dollars with State Appropriations, which they have just done.

The State of Georgia, as a partial result of Council Support, has put $100,000 appropriations into the P. & A. system. These are the types of activities that I think are very critical, activities that we need to continue so desperately. The only way for us to do that in Georgia is through the continuation of our State DD Council and the dollars congress awards for these activities.

The new bill 11761 should retain the ceiling on the allowable cost for the administration of this plan. It has been brought to my attention that this ceiling has been retained and I strongly support that.

The moneys allocated for this legislation are very minimal, and it is risky to leave it open that States could spend much of this money on administration. I would suggest you look into that and retain this ceiling on administration.

I thank you.

[Ms. Chesnut's prepared statement follows:]

Testimony of Zebe Chesnut, Planning Director, Georgia

April 5, 1978

My appreciation goes to you and your staff for allowing me to testify on behalf of and in the interest of the developmentally disabled in the State of Georgia. It is under the direction of the State Planning Council on Developmental Disabilities that I, as the Executive Director, speak.

The Georgia Council has developed a position paper supporting an extension of PL 94-103 that will not only preserve but strengthen the original intent of PL 91-517; legislation that will ensure the continuation of planning, coordination, advocacy, influencing and monitoring activities. The paper reflects their position; it does not reflect the reasons behind the position or the impact that the program has had in Georgia, has had in other states, and could have in allstates.

The Georgia program is the only one in the state with a mandate to ensure that the State is responsive to the service needs and to the rights of all its citizens with developmental disabilities. The mission statement of the council reads:

> "The overall mission of the Georgia Council is to facilitate the provision of quality services to persons with developmental disabilities; to promote the optimal use of federal, state, local and private resources in meeting the needs of the developmentally disabled; and to advocate for the human rights and dignity of the state's developmentally disabled"

The mandate of PL 94-103 is clear to each of you, and combined with that mission statement, one sees a massive responsibility. In the last three years the Georgia Council has become one of the most credible and respected entities concerned with a specific population in Georgia, spending 33% of it's allotment in planning,influencing,monitoring and general advocacy. The 36 member group is located in the office of theCommissioner of the Department of Human Resources and has direct access to Governor Busbee.

In the past year the Council has:

1. Influenced the Governor to require a comprehensive Master Plan for special education as a contingency for signing PL 94-142.
2. Influenced the Governor to get a joint agreement on the severely handicapped from the State School Superintendent and the Commissioner of the Department of Human Resources.
3. Influenced through resolutions and monitoring the establishment of a joint committee of the Departments of Human Resources and Education for the purpose of working on common problems as they relate to implementation of 94- 142.

4. Played a key role in passage of state legislation and appropriation affecting the handicapped including a Fair Employment Practice Act prohibiting hiring discrimination in state government and a mandate that special education training be required for school administrators and counselors. It has acted in the field of prevention through early screening for genetic disorders. Over 530 new special education teachers for implementation of 94-142 have been added, as well as transportation units commensurate with the additional educational units. It has helped obtain $100,000 in state appropriations for the state P and A system.
5. In the area of resource mobilization and coordination the council provides direct technical assistance to the state and to local communities in accessing other Federal, state and local programs, and as an official participant in the A-95 provides review and comment on all state plans and grant applications that relate to our target group.
6. Sponsored numerous demonstration projects in the area of services which have proven effective and transferred financial support to state responsibility.

I hope this minimal description of our activities will provide some answers to questions that have been asked concerning what happens with state monies in the formula grant system.

We believe that HR11764 is basically a very good bill, and wholeheartedly support:

1) The retention of the current definition.
2) The increased dollar support for the P and A system.
3) The changes in membership requirements for state and National councils.
4) The emphasis on planning, accountability and rights.
5) The requirement for state councils to plan for manpower development.
6) The changes in the roles and functions of the University Affiliated Programs.
7) The plan requirement for the National Advisory Council.
8) The elimination of construction activities.

We object to the elimination of the ceiling on the allowable costs for the administration. The monies allocated for this legislation are minimal, and not sufficient to risk the possibility of large expenditure for administration.

OBJECTION

We object to Congress requiring State Council's to spend 70% of their allotment to assist in the provision of services and 30% on planning activities.

RATIONALE

We must first undderstand the basic philosophy of the Developmental Disabilities Legislation, that is, it is not a service program. States must retain the flexibility to plan for and provide according to the unique needs of that state — based on that states own needs assessment. A national mandated percentage for any given area, whether service or planning does not allow for or recognize the individual needs of each state.

RECOMMENDATION

We recommend that the Committee oppose any restriction on allocation of State monies as it relates to the areas of services vs planning.

OBJECTION

We strongly object to Congress setting priority services for States.

RATIONALE

Priority service areas vary from state to state and from year to year. The State Council is in the best position to make that determination.

RECOMMENDATION

We recommend that Congress require state Councils to designate their own priority service areas in the State Plans and concentrate efforts in these designated areas.

CONCLUSION

I hope that you will take these comments and recommendations into consideration when the final draft of HR 11764 is prepared, and I express to you my appreciation for the efforts you are expending on behalf of persons who are developmentally disabled.

There is no doubt that we are here fighting for our State's right to continue to work in our state to see that the needs of persons who are developmentally disabled are met. That's what is utmost in our minds, as we review recommendations for extension of developmental disabilities legislation.

Gentlemen, this concludes my testimony.

Mr. **Rogers**. Thank you for an excellent statement.

Mr. **Carter**. I want to compliment the lady on her statement, particularly on those people who were taken from the institution and employed. They made—I have forgotten how much it was.

Ms. **Chesnut**. It is $100 a week.

Mr. **Carter**. In contrast to that, a lady called me last week, from the mental health association. She said that some of their people have made as much as $11 per week when they were employed. This is very much in contrast to what you have reported.

I want to compliment you on what you have done, but I bemoan the fate of those people in my area. I regret it.

Thank you, Mr. Chairman, for your indulgence.

Dr. **Watson**. The conference has obviously seen the handwriting on the wall of fairly serious divergences of opinion from many sources on what ought to happen to developmental disabilities and has, of course, therefore been accused of becoming a vested interest in itself in attempting to perpetuate its own activities.

I won't dignify that with any further discussion, except to say we did commission the activities of our own task force to come up with some recommendations for your consideration, looking at all the rest of the things that we knew to be in existence.

Roy Bruninghaus, Director for the State of North Carolina, will address himself to that and to those things which only the North Carolina DD Council wishes to speak to.

STATEMENT OF ROY V. BRUNINGHAUS

Mr. **Bruninghaus**. Thank you, Mr. Chairman.

I would like to first introduce my right arm, sitting on my right, my Assistant Director, Jane Smith.

Mr. **Rogers**. Mrs. Smith, we welcome you to the committee.

Mr. **Bruninghaus**. In the interest of time, I also will dispense with the reading of my written testimony and attempt to summarize our concerns and to address some of the issues which have been raised here this morning [see p. 401].

As I often do, I would also like to depart a little bit from Dr. Watson's introduction and suggest that I am speaking primarily on behalf of the council in North Carolina. I think that the work of the National Conference on Developmental Disabilities speaks for itself in the fact that we have been invited to appear in front of you, and we are extremely grateful for that opportunity to tell our story as best we can.

I would like to respond to the question about what it is that we actually do with our funds and how we do operate in the State of North Carolina.

You have in front of you on page 2 of my testimony a summary of our most recent accomplishments. You also have a two-page document which was prepared by my assistant director because her tenure with the council goes back a long time. It goes back a lot farther than mine.

I would like to summarize what you see there. Before I do that, I would like to indicate the process which we go through in North Carolina to do these kinds of things.

First of all, we take a look around, in some systematic fashion—and I guess that is what you planning—and we evaluate what is needed for services to persons with the four disabilities which this act addresses, and particularly paying attention to the severely handicapped and the multiply impaired. We try to determine what the client needs are at the community level for services and then what the system needs are, and that eventually gets us into policy analysis because, as you may know, the many, many dollars that are spent at the State level and at the community level are spent primarily in response to those agencies' policies, and that is where we look when we want to change things.

We then, after we determine what needs to be done, plan for and develop new program approaches. On the two-page sheet which you have, you see the word "demonstrate" many times. We started a lot of things in North Carolina, and some rather significant things are now being paid for by the State of North Carolina with taxpayers' dollars on a continuing basis.

In addition to planning for and developing these approaches, we then demonstrate these approaches. We take the risk with our Federal money that the Department of Human Resources or the Department of Public Instruction probably couldn't because they don't have that kind of money available and probably wouldn't because of the politics involved.

We demonstrate these approaches, to the State, and we involve them in asking us, does it work? How much does it cost? Does it get the job done?

We try to satisfy both the departments and the legislature that, in fact, this is a good program.

Then the fourth thing that we do is get the State to implement these programs with State dollars if they prove feasible and cost beneficial. I submit the list to you. It is a summary list, even at that, but you can get an idea of the kind of things we are doing.

Basically what we try to do is to cause the State to implement new programs, new laws, new policies and new funding approaches. On that last one, that sounds like some bureaucratic jargon, Dr. Carter, so I will refer you to the efforts on page 3 that we are talking about in my written testimony where you see there that we have convened a special interdepartmental task force on housing to provide a unified State effort in obtaining funds from the Federal programs for appropriate housing for all of our developmentally disabled. That is what I mean when I saw new funding approaches. We try to pull together the agencies that could respond to the housing needs of the handicapped to access their funds.

Mr. CARTER. I think that is innovative and makes good sense. I don't think that is bureaucratese.

Mr. BRUNINGHAUS. Thank you.

Now in respect to the bill which has been prepared by your committee, first of all, I would like to express our belief that H.R. 11764 is basically a very good bill. We wholeheartedly support the retention of the current definition of developmental disabilities. It is hard enough to explain, I think, what we do in terms of trying to serve the population outlined in Public Law 94–103 without going into any long definition and explanation based on some kind of functional approach, although I suspect somewhere down the line in this country we are going to a noncategorical approach to serving the handicapped.

But I think we need a little bit more time struggling along under the current definition to make sure this particular population is served.

The second point that we wholeheartedly support is the increased dollar support for the protection and advocacy system which, in many States and in our State, is beginning to make its impact felt in terms of opening up, most particularly, Dr. Carter, school systems which are rebelling against implementing 94-142. We are using our protection and advocacy system to bring heavy administrative activity to open up those systems and also engage in both individual suits and class action suits, as appropriate.

We had a similar problem with regard to integration, as you know, in North Carolina, and of course I guess we still do in terms of our university system. But the point is that it is even more difficult in some of our rural counties to get the handicapped into the school system; perhaps more so than other minorities.

The third point that we would like to support in H.R. 11764 is the changes in the membership requirements for both the National Advisory Council and for the DD councils. We believe that having handicapped people on the council and also their parents and their guardians is one of the greatest assets of our program.

We also support the emphasis on the planning and accountability and rights that is contained in the bill.

We also support the requirement for state councils to plan for manpower development. It does not do much good to develop a service program if you don't have anybody to run it, to be there or qualified to be there. We try to stress both quantity and quality on that.

We also support the changes in the roles and functions of the university affiliated programs, the plan requirement for the National Advisory Council and the elimination of construction activity.

With regard to the priority service areas, which is an issue, let me simply say that we believe that while setting priority services is an important thing for a council to do, we would prefer that the States be required to assess those four priority areas on their own, if you will, rather than have Congress, in its infinite wisdom, suggest what the priorities should be for the State of North Carolina or for any other State.

I think that with regard to the 70 percent rule, let me suggest to you and refer you back to my discussion of how we do things. We need some flexibility to spend our funds to carry out the four activity areas which I indicated to you at the beginning of my testimony. In some years we may get heavily involved in starting up programs such as the ones listed. In other years, we may get heavily involved in legislative activity and bureaucratic jawboning. In other years we may get heavily involved in evaluation.

Those things will vary from year to year. So we really have a problem with an arbitrary percentage placed on us to spend our funds. We think that is a prerogative that we, in fact, should be allowed to keep. I think there is enough accountability built into your bill, and there can be enough accountability built into the regulations that would come along with new legislation that would make sure that we are not playing fast and loose with the funds.

The final point I would like to make is that we are concerned about a fair and continuing and appropriate evaluation of this program. Now I call your attention to the chart which was, I believe, submitted yesterday by Dr. Boggs.

With all due respect, and I think it is an excellent chart. But what this chart does not tell you is the fact that there is significant variations in the amounts of money which each of these States get. If you have only $150,000 to spend, and many councils—Artis here is a perfect example—have that, and when you recognize that our autistic home for children in Greensboro, N.C., costs $80,000 a year to operate, you are not going to get much back for the buck if you put 70 percent of that $150,000 into services.

Yet, on the other hand, if you have what California has or what Ohio has or what Illinois has, or even what we have or what Florida has, you can afford to start some good service programs and you can deliver some direct services.

There is a catch in that, too. I think if you are going to provide direct services, you have an obligation to your clients to continue those services. Our money is in jeopardy every 3 years.

I will submit to you and recommend, as I have in my written testimony, that the Secretary of HEW be ordered by the Congress to conduct a continuing and fair evaluation of what it is that we have been mandated to do so that we can justify our existence in a much more effective fashion.

With that, I will close. Again, thank you very much for the opportunity to tell our story. I will be happy to answer any questions about our program.

[Testimony resumes on p. 412.]

[Mr. Bruninghaus' prepared statement and attachment follow:]

STATEMENT OF TESTIMONY

BEFORE THE

HEALTH AND ENVIRONMENT SUBCOMMITTEE

ON HR 11764 DEVELOPMENTAL DISABILITIES AMENDMENTS OF 1978

Respectfully submitted by:

ROY V. BRUNINGHAUS
Executive Director,
North Carolina Council on
Developmental Disabilities

April 5, 1978

INTRODUCTION:

Mr. Chairman, members of the subcommittee, my name is Roy Bruninghaus. I am the Executive Director of the North Carolina Council on Developmental Disabilities, and I am also the Vice Chairman of the Legislative Task Force of the National Conference on Developmental Disabilities. I will speak, however, primarily on behalf of the North Carolina DD Council since the President of the National Conference and the Chairman of its Legislative Task Force are accompanying me on this panel.

BACKGROUND:

It is the consensus of the North Carolina Council on Developmental Disabilities that the Developmental Disabilities Act, P.L. 94-103, should be renewed and that the continuation of the DD program should preserve the original intent of P.L. 91-517, as amended by P.L. 94-103 which emphasizes the planning, influencing, and accountability roles of DD Councils. The DD program is the only program in the state of North Carolina which has a mandate to ensure that the state is responsive to the service needs and to the rights of all of its citizens with developmental disabilities. It is a very large, complex task, but we have adequate state and federal funds to do this job well and our Council and staff are making great progress.

Because we have been perceived by the state as a planning and influencing program, we are located in the Office of the Secretary of the Department of Human Resources where we are required by our State DD law to advise her in all matters related to providing services to persons with developmental disabilities. From this vantage point, we have been able to participate in significant planning and policy-making activities with the Department and to use our funds to take a lead role in developing and demonstrating new ways to solve some of our oldest problems.

The Council's most recent accomplishments include:

(a) the design and passage of a Limited Guardianship Law,

(b) the establishment of a Laboratory to measure the anticonvulsant drug levels in the blood of persons with Epilepsy in order to maintain precise drug levels for the control of seizures,

(c) the planning and development of a Case Management System for statewide application if the demonstration programs meet their objectives and satisfy the concerns of the Department and the Legislature,

(d) the demonstration of a model program for Mentally Retarded Youthful Offenders in a medium security Prison in order to reduce their stay and their rate of return once released,

(e) the establishment of the first Group Home for Autistic Children in the state,

(f) the establishment of a High Risk Screening Pilot Project in the newborn nurseries of six counties which coordinates the efforts of the public and private sector and tracks and coordinates services to high risk children, and

(g) the provision of Policy Guidance to the Secretary of the Department of Human Resources which concentrates on the areas of: (1) primary and secondary prevention, (2) institutional reform, (3) case management, and (4) the implementation of Section 504 of the Rehabilitation Act of 1973 and the Education for All Handicapped Children Act of 1975, (P.L. 94-142).

The Council is convening a special interagency Task Force on Housing to provide a unified state effort in obtaining funds from Federal programs for appropriate housing for all the developmentally disabled. The Council is funding four field staff positions for the DD Protection and Advocacy System. The Council is providing staff support to the Governor's interagency Task Force on Transportation which will develop a plan to meet the transportation needs of persons who live in rural areas, particularly the handicapped. The Council is providing staff to the Secretary of the Department of Human Resources to coordinate and to develop the efforts of volunteer manpower to assist agencies which provide services to the developmentally disabled across the state. The Council this year will analyze the policies of all state agencies to ascertain their responsiveness to the service needs and to the rights of persons with developmental disabilities.

Mr. Chairman, I review these activities because I want to highlight how we have put the focus of the current DD law into action and what we will lose if Congress changes that focus in its amendments to the DD law.

POSITION ON HR 11764: Areas of Agreement

We believe that HR 11764 is basically a very good bill. We wholeheartedly support: (1) the retention of the current definition of Developmental Disabilities, (2) the increased dollar support for the Protection and Advocacy Systems, (3) the changes in membership requirements for both the National Advisory Council and the DD Councils, (4) the emphasis on planning, accountability and righ[illegible] (5) the requirement for state Councils to plan for manpower development, (6) the changes in the roles and functions of the University Affiliated Programs, (7) the plan requirement of the National Advisory Council, and (8) the elimination of construction activities.

POSITION ON HR 11764: Areas of Disagreement

(A) PRIORITY SERVICE AREAS

Objection:

We object to the Congress setting priority services for states, and we question on what basis has Congress determined that the four (4) services in the bill are the priority services for North Carolina.

Rationale:

There are sixteen (16) service areas for persons with developmental disabilities. Priority service areas vary from state to state. States should decide what those priority areas are; not Congress.

Recommendation:

We recommend that Congress require State Councils to designate four priority service areas in their state plans and concentrate their program planning, influencing, and evaluating activities in these areas.

(B) 70% RULE

Objection:

We object to the Congress requiring State Councils to spend 70% of their allotment "to assist in the provision of services" to persons with developmental disabilities.

Rationale:

The essence of the developmental disabilities legislation is the planning, influencing, and evaluating role of State Planning Councils, the protection of rights by the Protection and Advocacy Systems, and the training of manpower by the University Affiliated Programs.

To require a Planning Council to spend 70% of its funds in the provision of direct services is a contradiction of their mandate.

Councils cannot provide direct services on a continuing basis and carry out their mandate for two reasons:

(1) there is an insignificant amount of money in the face of the need, and

(2) there is no permanence to DD funding.

Both reasons place a cruel burden on both those who serve and those who are served in terms of frustrated expectations and undue hardship.

Councils are most effective in influencing the state to develop quality services when they: (a) fund pilot or demonstration projects, (b) evaluate the success of such projects, (c) develop strategies prior to initial funding to insure permanent state funding when they are completed and proven successful, and (d) develop the necessary support and commitments for statewide application.

This process may require a Council in one year to spend more money on planning for the development of such projects than in operating them. In some years more funds may be allocated by a Council for operating the projects than for planning them. And in some years additional funds may be allocated for intense evaluations and the development of replication strategies for the state.

It is unreasonable for Congress to curtail or restrict this flexibility by placing any arbitrary per cent on the amount of funds a Council is required to spend on providing direct services.

Recommendation:

We recommend that paragraphs 4 A, B, and C of Section 133, "Provision of Priority Services" be stricken from the bill.

(C) EVALUATION

Objection:

We object to the fact that the Secretary has not conducted a fair, effective, and continuing evaluation of the DD program.

Rationale:

We are asked to come before the Congress and justify our existence every three years. Yet the Secretary has not assisted us by evaluating the DD program on the basis of its mandate.

DD Councils are mandated to plan for, to influence the development of, and to evaluate the quality of services for persons with developmental disabilities. Yet critics evaluate Councils on the basis of the direct services which they provide. This is not only unfair evaluation, but it is also a major contribution to the pervasive misunderstanding of what the focus of the DD program is.

Recommendation:

We recommend that the Congress require the Secretary to develop a system to evaluate the impact of State Councils' planning, influencing, and evaluating activities.

CONCLUSION:

Mr. Chairman, this concludes my testimony. Please let me emphasize again that we support most of HR 11764. It is a good bill, and we hope that you will take our recommendations into consideration when the final draft is prepared.

ACCOMPLISHMENTS OF THE NORTH CAROLINA COUNCIL ON DEVELOPMENTAL DISABILITIES

- Pioneered the implementation of Statewide Screening for Phenylketonuria.
- Supported and assisted in the development of Legislation for Child Abuse and Neglect Reporting.
- Assisted in the development of and supported changes in Legislation to allow more educational programs for persons with Developmental Disabilities.
- Assisted in the development of and supported Legislation authorizing grant-in-aid subsidies to sheltered workshops and day care programs.
- Pioneered the development of and assisted in the establishment of the first genetics counseling center in North Carolina.
- Assisted in and supported the development of a specialized facility for persons in the correctional system who have developmental disabilities.
- Assisted in and supported the establishment of sheltered residential facilities in communities.
- Endorsed and supported Legislation for mandatory licensing of day care centers.
- Assisted in and supported the development of day care, research, and sheltered employment facilities.
- Developed and supported the Special Olympics in North Carolina.
- Supported educational efforts to assure that all children receive immunizations to prevent diseases that could result in developmental disabilities.
- Sponsored "Careers Days" at colleges and universities across the state to introduce students to the variety of health related careers.
- Sponsored "PACE" students to work in community programs serving the developmentally disabled.
- Developed local Councils on Developmental Disabilities to plan services for the population they represent.
- Developed materials and worked with communities in providing religious programs for developmentally disabled persons in their home churches.
- Developed and influenced the passage of Legislation providing guardians, with powers limited by the ability of the ward, for persons with developmental disabilities.

- Provided training to persons affected by the limited guardianship legislation.
- Demonstrated the impact of screening of infants to detect developmental disabilities at an early age.
- Developed and supported community residential facilities so that persons with developmental disabilities are able to remain in their home communities.
- Developed and supported the establishment of a laboratory to analyze the level of anti-convulsant drugs in the blood of persons with seizure disorder.

Mr. **Rogers**. Thank you, Mr. Bruninghaus.

Dr. Carter.

Mr. **Carter**. Thank you, Mr. Chairman.

I particularly wanted to compliment the gentleman from Ohio, Mr. Brown, who gave such a nice presentation. I think he is eminently worthy of being on the board in Ohio.

I have looked over the program here that you have from North Carolina and I find, in your infinite wisdom, you have done quite well. I am not going to castigate you or flagellate you for something that is not done. I think that is pretty well planned.

However, I hope that you would find funds somewhere for that institution that you have for the autistic children. I believe you said it costs you $80,000 a year to run it. I hope you will do that.

Of course, apparently there are many problems. Again, you must have planning; you must have coordination; you must have funds for that. The impact of the funds should be to assist those who have disabilities. Those people who are closer to those who have the disability perhaps realize this more than anyone else. Planning is very necessary, and I support funds for that. But without training people to teach and to help these people, we would certainly be in sad shape.

Thank you, Mr. Chairman.

Mr. **Rogers**. Thank you, Dr. Carter.

As I understood it, the council generally supports the minority view——

Mr. **Brown**. Yes.

Mr. **Rogers** [continuing]. Regarding the definition rather than the majority.

Dr. **Watson**. Yes. Or the current definition.

Mr. **Rogers**. Does the law need to be clarified as to who is responsible for planning and establishing the priority? Is there any confusion there?

Dr. **Watson**. There is confusion in the law and there is absolutely unresolved confusion in the regulations and guidelines. It must be clarified.

Mr. **Rogers**. What should it be?

Ms. **Chesnut**. Can I speak in terms of this in Georgia? We feel strongly that because the administrative agency in Georgia is one small agency, the DD population in that plan must reflect the activities and gaps in programing for several, possibly nine, Federal-State programs. So we see it almost an impossible task to ask an agency to write a comprehensive plan that includes nine different Federal-State programs.

I think this needs to be clarified definitely in the new legislation that the State Development Disabilities Planning Council is responsible for development of the plan.

The same thing in the establishment of priorities. I don't think that one agency, even if it is the human service agency can establish comprehensive priorities—labor is a very big part of the need of services for the developmentally disabled, so they also must speak and must also listen. So we feel strongly that the council is best for establishing priorities.

Another advantage of the council is that you have some very real input in terms of one-third of that council membership being consumers and consumer representatives. You also have providers of services; those people in the community who reside many miles from our State capital. They need to be involved in planning as well as the State agencies.

We feel that should be cleared, and it would be helpful to us as a council if it could be cleared in the legislation.

Mr. **Brown.** May I speak to one qualification that I feel needs to be more defined, and that is what is a consumer. In Ohio, we have gone through almost total reorganization based on the fact that no one is quite sure what a consumer is.

For example, I made reference to the fact that I cannot, in Ohio, under current law be classed as a consumer because I am also an agency representative. I think that is unfair because, as Mr. Carter has said, I think we need more of our own people serving our own people, and if they do that, then they cannot, under current law, participate as consumers.

Mr. **Rogers.** May I suggest that you might want to submit to us the language that you think would carry out your thinking on the definition of consumer.

We will be glad to look at that.

Dr. **Watson.** We will be very pleased to do so.

[The information requested was not available to the subcommittee at the time of printing.]

Mr. **Rogers.** Thank you so much. The committee is grateful for your presence here today.

Dr. **Watson.** I have to say, sir, this was very educational for us. The previous panel said more good thngs about the DD Council system in one place than I have heard in 3 years.

I thank you for the opportunity.

Mr. **Rogers.** The committee will stand in recess until 2 o'clock this afternoon.

[Whereupon, at 12:15 p.m., the subcommittee recessed, to reconvene at 2 p.m., the same day.]

AFTER RECESS

[The subcommittee reconvened at 2 p.m., Hon. Paul B. Rogers, chairman, presiding.]

Mr. **Rogers.** The subcommittee will come to order please, continuing our hearings on Development Disabilities Act Amendments of 1978. I would like to remind witnesses again that we are under a time constraint. If those who give testimony could hold it to 10 minutes and those on panels to 5 minutes each, it will be helpful to the committee.

The first panel this afternoon is a panel of State agencies. Mr. Gareth Thorne, who is the commissioner of the Connecticut Department of Mental Retardation, Hartford, Conn., and Dr. Leonard Ganser, who is the administrator of the Division of Community Services, Wisconsin Department of Health and Social Services, accompained by Mr. Harry Schnibbe and Ms. Jayn Wittenmyer, on behalf of the National Association of State Mental Health Program Directors.

We welcome each of you to the committee. Your statements will be made a part of the record in full.

Mr. ROGERS. You may proceed as you desire.

STATEMENTS OF GARETH THORNE, SECRETARY-TREASURER, NATIONAL ASSOCIATION OF STATE MENTAL HEALTH RETARDATION PROGRAMS DIRECTORS, INC.; AND LEONARD GANSER, M.D., ON BEHALF OF NATIONAL ASSOCIATION OF STATE MENTAL HEALTH PROGRAM DIRECTORS, ACCOMPANIED BY HARRY SCHNIBBE, EXECUTIVE DIRECTOR; AND JAYN WITTENMYER, EXECUTIVE DIRECTOR, WISCONSIN DEVELOPMENTAL DISABILITIES COUNCIL

Mr. THORNE. Mr. Chairman, my name is Gareth Thorne. I currently serve as the commissioner of the Connecticut Department of Mental Retardation. I am here today representing the National Association of State Mental Retardation Program Directors, which is an organization of officials in the 50 States who are directly responsible for the provision of today and residential services to over one-half million mentally retarded and other developmentally disabled citizens.

I have a statement that has been submitted and I will take from the general statement certain areas that I think might be of interest to you [see p. 418].

Mr. ROGERS. That would be helpful.

Mr. THORNE. Thank you, sir.

For the purpose of today's testimony, I plan to focus only on the most fundamental barriers to accomplishing the goals of the developmental disabilities program. I would like to relate these broad issues to speculative revisions proposed in H.R. 11764.

One of the basic difficulties associated with the program from its onset has been the diffuse set of statutory goals. The gap-filling philosophy underlying the legislation has proved to be a rather nebulous target for many State councils and agencies. Lacking clear legislative or administrative guidance concerning expenditure priority States have been faced with the unenviable task of addressing a seemingly endless need of service needs with woefully inadequate financial resources.

As a result, even where appropriate, service priorities have been identified and activities initiated, the impact has been minimal due to the massive scope of the problem.

The reasons for the mediocre performance of many States is quite complex. It seems clear that the original planners of the legislation underestimated the difficulty of influencing the policies and practice of large human service systems through a gap-filling or role-modeling approach.

H.R. 11764 addresses this problem by identifying four priority service areas: Individual client management services and infant development services, alternative community arrangement services, and nonvocational development services. The national association endorses the target services approach, incorporated in the Roger bill for the following reasons.

First, it leaves the individual States some flexibility to choose the service areas in which Federal dollars are most needed, while at the same time requiring each jurisdiction to focus its federally supported activities on clear, attainable service goals.

Second, it establishes a viable relationship between the service objectives of the program and the Federal aid available to help meet these objectives.

Third, it permits an orderly expansion of the program as Federal support increases in further fiscal years.

While the association views the above provisions of H.R. 11764 as a keystone to improving operation of the current development disabilities program, we would like to recommend one relatively minor change in the bill as introduced. Section 133(b)(4)(B)(i) (I) and (II) should be revised to allow a State to choose whether to focus on one or two service priorities as long as the total section 131 appropriation is below $60 million and on two or three priority areas as long as the appropriation is below $90 million. The language of the current bill is contradictory.

Section 133(b)(4)(ii) seems to suggest that States would be permitted to focus on one area while the other section, 133 (b)(4)(B) (ii) (I) and (II), indicates the States must focus on two or three service priority areas respectively.

What we are basically saying is that especially minimum allotment States should be given the option of focusing on fewer priority areas if a council agrees that a greater overall impact would be achieved.

Mr. ROGERS. I think that makes sense.

Mr. THORNE. In terms of the general area of clarifying the planning service advocacy roles of the council, there continues to be some problem of clarification. While these changes that were made in the proposed bill were intended to clarify the responsibilities in the council, in fact, there continues to be a significant State-to-State variation in the scope and types of planning and direct service activity supported.

As a result, it is impossible to pursue national goals under the current legislation as presently structured. The bill under consideration, the Rogers bill, would attempt to resolve the confusion surrounding the current planning and service advocacy roles of the council by making it clear at least 70 percent of the State's allotment must be used for the provision of services in one or more of the priority areas identified in the bill.

In addition, a stronger emphasis would be placed on development of operational plans in the service priority area selected by the State. Our association agrees that increased emphasis should be placed on operational planning.

To be effective, the planning and implementation functions must be part of the cycle process under the current law. However, the council usually lacks both control over the necessary resources and the political backing to assure its plans are implemented.

In addition, significant discrepancis often exist between the global, statewide plans developed by the council and the operational plans prepared by various State and local agencies engaged in serving developmentally disabled clients. Hopefully the Rogers bill will minimize such discrepancies by focusing the council's planning efforts on the selected priority areas and channeling the bulk of the State's section 132 allotment to carry out the plan once it is developed.

Although we agree with the primary thrust of the Rogers bill, we recommend that the subcommittee place some reasonable time limit on the grandfather clause contained in section 133(b)(4)(B)(iii) of the bill. Therefore, we suggest that section 133(b)(4)(B)(iii) be applicable only in the fiscal year 1979 year in order to permit affected States to make transition to the new requirements of H.R. 11764.

This is addressing, I think, the problem that Dr. Carter has been mentioning this morning, of getting some money into actual service provisions and limiting the continuation of putting most of the money in the planning.

I will skip along here. In terms of definitions, because definitions have been always a problem and have been addressed in these hearings and in others, I would just like to point out that while we, in general, favor the approach of the definition proposed by both the majority and the minority members of the national task force on the definition of developmental disabilities, clearly the criterion for program eligibility should be based on the functional service needs with severe disabilities originating in chlidhood, rather than upon diagnostic labels. Such labels provide little practical guidance to the program administrator charged with the task of designing an effective service programs.

Basically, on balance the association recommends that the subcommittee proceed with great care before approving any significant expansion in the current statutory definition. A completely functional definition may be a worthy objective.

However, given the existing gaps in services to the disability groups currently covered and the differences in the service needs and delivery systems and groups that would be added under the task force's major definition, we simply see no practical way to avoid drawing some categoric parameters around program eligibility.

Now as a commission of a large department in the State of Connecticut and the developmental disabilities program is lodged in the department for administrative purposes, I would like to make a general comment which I think summarizes to some extent what the State directors are attempting to do. We certainly have always strongly advocated planning. We have been pleased certainly in Connecticut with the planning effort that has been made by the Developmental Disabilities Council. It has been a very hard working group, a very highly involved group and has worked very cooperatively with all the agencies.

However, there is a point in time when planning has to come to some specific and end goal, some objectives. In other words, we plan to the point of becoming almost an exercise in futility. It is very frustrating for people to plan and plan and plan and not be able to implement planning.

Money, of course, is a major object. The developmental disabilities program has never been funded to the extent that implementation of planning has been carried out as a part of the Federal contribution. It has always been left up to the States to generate the funding.

My personal belief is that when we are looking at planning in the perspective of coming up with a total, overall comprehensive plan we end up with something that is not attainable and quickly gets put on somebody's shelf and gather dust and we go to the next set of plans when we change administrations or Federal laws or whatever it may be.

In my position my hope would be that our planning be directed to specific goals, to specific major areas that need attention, that the funds that come to the States be spent for the development of programs, direct service programs, that will meet the needs of people and also directed to capacity building of in-place agencies.

We believe very strongly in a single agency designation for the DD program, particularly an agency that has already within the State structure a level of credibility and service provision that cuts across a wide swath and that by building capacity in those agencies or in that agency and by limiting planning to specific priority areas and by implementing plans as a process and building as we go, I think that we would make a lot more productive use of Federal dollars and State dollars rather than trying to take on the world and have a solution for everything.

[Testimony resumes on p. 428.]

[Mr. Thorne's prepared statement follows:]

STATEMENT OF TESTIMONY
at hearings on the
DEVELOPMENTAL DISABILITIES AMENDMENTS OF 1978
H.R. 11764 (Rogers)

Respectfully submitted,

to the

Subcommittee on Health and the Environment

Committee on Interstate and Foreign Commerce

U. S. House of Representatives

The Honorable Paul G. Rogers, Chairman

Gareth Thorne, Commissioner
Connecticut Department of Mental Retardation

and

Secretary-Treasurer, National Association of State
Mental Retardation Program Directors, Inc.

April 5, 1978

Mr. Chairman and distinguished members of the Subcommittee, I appreciate this opportunity to appear before you to present the views of the National Association of State Mental Retardation Program Directors on the Developmental Disabilities Amendments of 1978 (H.R. 11764).

The membership of our Association consists of the designated officials in the fifty states and territories who are directly responsible for the provision of residential and community services to a total of over ½ million mentally retarded children and adults. As a result, we have a vital stake in a variety of federal health, education and social welfare programs. In recent years, as states have begun to emphasize the development of a wide range of residential and daytime alternatives to large, publicly-operated institutions, the number, scope and complexity of federal assistance programs impacting on state mental retardation agencies has increased tremendously.

This morning I would like to outline for the Subcommittee the Association's view on the Developmental Disabilities program, one small but important component of the federal government's array of assistance programs which impact on mentally retarded citizens. The state mental retardation agency serves as the designated unit to administer federal DD formula grant funds in approximately two-thirds of the states. In addition, since an estimated 65 percent of the 5.4 million developmentally disabled persons requiring services have a primary diagnosis of mental retardation, even those state MR agencies which do not serve as the designated DD unit, have a vital stake in the success of the Developmental Disabilities program. For this reason, it seems both timely and appropriate to describe our experiences as state officials who have been intimately involved in the day-to-day operation of the program since its inception some 6½ years ago.

As initially conceptualized, the Developmental Disabilities program was intended to be a planning, coordinating and gap-filling mechanism which would help consumer representatives, service providers and responsible state officials to rationalize the expanding array of federal and state programs aimed at financing and delivering services to some of our society's more severely disabled citizens. In practice, however, the program has not achieved the lofty expectation which many consumer advocates and professionals held in 1970. At the same time, the fundamental goals which the original legislation addressed are, if anything, even more meaningful today than they were 6½ years ago.

I recognize that this Subcommittee will receive a wide range of views on the existing barriers to accomplishing the goals of the Developmental Disabilities program. Clearly, there are a variety of issues to be considered. For purposes of today's testimony, however, I plan to focus only on those issues which appear to be most fundamental and farreaching. In addition, I will attempt to relate these broad issues to the specific legislative revisions proposed in H.R. 11764 (Rogers).

1. Need for Statutory Service Priorities

One of the basic difficulties associated with the program from its on-set has been the diffuse set of statutory goals. Despite glaring deficiencies in the range and scope of services available to the developmentally disabled in all states, the gap-filling philosophy underlying the legislation has proven to be a rather nebulous target for many state councils and agencies. Lacking clear legislative or administrative guidance concerning expenditure priorities, states have been faced with the unenviable task of addressing a seemingly endless array of service needs with woefully inadequate financial resources. As a result, even where appropriate service priorities have been identified and activities initiated, the impact has been minimal due to the massive scope of the problem.

The designers of the DD legislation, however, never anticipated that the program would furnish basic operating support for a discrete set of services to eligible recipients. Instead, they envisioned federal DD service dollars as having a catalytic impact on the expenditure of funds available through a wide variety of generic and specialized service systems within each state (e.g., education, vocational rehabilitation, health, mental health, mental retardation, crippled children, etc.). In other words, when linked with the planning and coordinative activities of the state council, DD funds were supposed to have an influence on the activities of the mega-service systems disproportionate to the actual number of federal DD dollars expended.

In practice, however, federal DD service grants appear to have had only a limited and sporatic impact on the overall pace and direction of change in many states - despite the notable accomplishments which have occurred in a few jurisdictions. The reasons for the mediocre performance of many states are quite complex. However, it seems clear that the original planners of the legislation underestimated the difficulty of influencing the policies and practices of large human service systems through a gap-filling or role modeling approach.

One lesson, therefore, which can be derived from our initial experience with the DD program, is that a somewhat more targeted and clearly defined set of service objectives is essential if the program is to have a meaningful impact on expanding and improving services.

H.R. 11764 addresses this problem by identifying four priority service areas - individual client management services; infant development services; alternative community living arrangement services; and non-vocational social-developmental services. Initially, each state would be required, by law, to select two of those four priority service areas in which to concentrate its efforts. Until appropriations under Section 131 reached $60 million annually, each state would be required to expend at least $100,000 or 70 percent (whichever was higher) of its annual allotment on service activities associated with the two identified priority areas. Once the annual appropriation was between $60 and $90 million, a state would be required to expend 70 percent of its funds (or $100,000, if higher) on three priority service areas. When annual appropriations exceeded $90 million, a state would have to expend 70 percent of its formula grant allotment on all four priority service areas.

NASMRPD endorses the target services approach incorporated in the Rogers bill because: (a) it leaves the individual states some flexibility to choose the service areas in which federal dollars are most needed while, at the same time, requiring each jurisdiction to focus its federally supported activities on clear, attainable service goals; (b) it establishes a viable relationship between the service objectives of the program and the federal aid available to help meet these objectives; and (c) it permits an orderly expansion of the program as federal support increases in future fiscal years.

While the Association views the above provisions of H.R. 11764 as the keystone to improving the operation of the current Developmental Disabilities program, we would like to recommend one relatively minor change in the bill, as introduced. Section 133(b)(4)(B)(ii)(I) and (II) should be revised to allow a state to choose whether to focus on one or two service priority areas as long as the total Section 131 appropriation is below $60 million dollars and on two or three priority areas as long as the appropriation is below $90 million. The language of the current bill is contradictory. Section 133(b)(4)(ii) seems to suggest that states would be permitted to focus on one area, while Section 133(b)(4)(B)(ii)(I) and (II) indicates that states must focus on two and three service priority, respectively. NASMRPD believes that states, especially minimum allotment states, should be given the option of focusing on fewer priority areas if the agency and council agree that a greater overall impact can be achieved.

2. Clarifying the Planning/Service/Advocacy Roles of the Council

The original Act was built upon the assumption that a coalition of consumer representatives, professionals and state officials - as represented by the state council - would be in the best position to identify gaps in services and stimulate action to fill them. It was argued that the priority needs of the target population varied significantly from state to state and, therefore, each state should be given the flexibility to address its needs through a combination of service, planning and gap-filling activities. Some states have found this approach to be quite workable and, to a greater or lesser extent, the expenditure of federal DD dollars and the activities of state councils have had a favorable impact on the initiation and improvement of services. Many other states, however, have achieved little or no progress in striking a balance between their planning, service, and advocacy roles.

The Act itself, and related administrative regulations and guidelines, offers state councils little in the way of practical advice on how to integrate these distinct but interactive sets of activities into a total state program. Decisions on how much time, effort, and money should be devoted to planning, improving services, and advocacy are left almost entirely to the discretion of each state. Despite the provision of an extensive array of national and regional technical assistance over the past five years, many state councils still appear to be struggling to sort out their appropriate roles and the best ways of pursuing them.

In the 1975 amendments to the Act (P.L. 94-103) Congress placed greater statutory emphasis on the council's role as a systemic advocate and as a focal point for comprehensive state-wide planning. This fact is reflected in the revised name of the council and in the increased statutory emphasis on those aspects of the council's role. Conversely, the council's responsibility for awarding service grants was restricted.

While these changes were intended to clarify the responsibilities of the council, in fact, there continues to be significant state-to-state variations in the scope and types of planning and direct service activities supported through DDSA funds. As a result, it is all but impossible to pursue national goals and objectives through the program as presented structured.

The Rogers bill would attempt to resolve the confusion surrounding the current planning, service and advocacy roles of the council by making it clear that at least 70 percent of a state's allotment must be used for the provision of services in one or more of the priority areas identified in the bill. The designated state agency, in cooperation with the state council, would continue to be responsible for submitting a state plan and conducting a review of needs in the four priority service areas each year. However, a stronger emphasis would be placed on the development of operational plans in the service priority areas selected by the state.

NASMRPD agrees that increased emphasis should be placed on operational planning. To be effective, the planning and implementation functions must be part of a cyclical process. Under current law, however, the council usually lacks both control over the necessary resources and the political backing to assure that its plans are implemented. In addition, significant discrepancies often exist between the global, state-wide plans developed by the council and the operational plans prepared by various state and local agencies engaged in serving developmentally disabled clients. Hopefully, the Rogers bill will minimize such discrepancies by focusing the council's planning efforts on the selected service priority area(s) and channeling the bulk of the state's Section 132 allotment to carrying out the plan once it is developed.

Although we agree with the primary thrust of the Rogers bill, we recommend that the Subcommittee place some reasonable time limit on the "grandfather clause" contained in Section 133(b)(4)(B)(iii) of the bill. While it is true that some states have devoted a relatively large percentage of their DDSA allotments to planning activities and, in such instances, it may be disruptive to require them to expend 70 percent on priority service area(s) in FY 1979, we see little justification for continuing such an arrangement indefinitely. In fact, such action would undermine the basic intent of the Rogers bill - i.e., to place stronger emphasis on the provision of direct services in all states. For this reason, we suggest that Section 133(b)(4)(B)(iii) be applicable only in FY 1979 in order to permit affected states to make an orderly transition to the new requirements of H.R. 11764.

3. Impacting on Generic Federal Funding Programs

One of the basic tenets of the Developmental Disabilities Act is that, because of the scope and longevity of the target population's needs, maximum progress can be achieved through an inter-agency effort to access and coordinate the activities of a variety of health, education, rehabilitation and social services agencies which have a role to play in serving the developmentally disabled. While convincing arguments for this approach have been advanced over the years, in most states the program has had little or no influence on the policies and practices of the federal/state service programs mentioned in Section 133(b)(2)(B) of the bill.

Among the reasons why most state councils have had only a minimum impact on policies and expenditure priorities affecting developmentally disabled persons under such major federal-state programs are: (a) the broad nature of the council's mandate and the limited time and money available to pursue this area; (b) the complexity of these huge human service programs; (c) the absence of specific legal provisions for enforcing interagency cooperation; (d) the lack of a planning orientation among most consumer and provider members of councils; (e) the difficulty of altering statutory and regulatory policies which limit participation by DD individuals from a state level; (f) the inadequate data upon which to base sound planning strategies; and (g) the high turnover rate among agency, consumer and provider representatives on councils.

Under the Rogers bill, the council would retain its systemic advocacy role and continue to be responsible for reviewing a variety of federal-state plans which impact on developmentally disabled persons. In addition, the DD state plan still would have to contain a description of the extent and scope of services provided to the developmentally disabled under such federally assisted programs as education for the handicapped, vocational rehabilitation, public assistance, medical assistance, social services, maternal and child health, crippled children's services, comprehensive health and mental health and such other plans as the Secretary of HEW might specify.

In spite of past problems, we agree that it makes sense to assign the council responsibility for identifying barriers to full participation by the developmentally disabled in publicly funded human service programs. Given the diversity of funding streams and multi-agency involvements in all states, clearly this is an important council function. Hopefully, by clarifying the role of the council and targeting DD expenditures on a limited set of service priority areas, councils will be able to devote increased time to this important role.

The Rogers bill also would require the reorganized National Advisory Council on Services, Facilities, and Rights of the Developmentally Disabled to prepare, and up-date annually, a national, five year plan for the target population. We agree that such a national plan would be most helpful, especially if it focused on the identification and elimination of existing barriers to the effective utilization of various federal generic and specialized resources on behalf of developmentally disabled persons. However, given the apparent opposition of the Administration to continuation of the Council and the general antipathy of OMB to statutory set asides for advisory committee staff (as proposed in Section 108(d) of the bill), we have serious reservations that the Council can develop such a national plan. The proposed composition of the Council and the fact that it would retain most of its current functions only adds to our doubt that the National Council could complete the type of searching analysis and foresighted overview of nationwide efforts on behalf of developmentally disabled persons which is so desperately needed.

One possible approach which the Subcommittee may wish to consider is to require that a portion of the special project grant funds, appropriated under Section 145, in FY 1979 and subsequent fiscal years, be used to support background studies and analyses which will assist the National Council in developing such a comprehensive five year plan.

4. Differenciating the Roles of Council and Administering Agency

The 1970 legislation (P.L. 91-517) made it clear that the council was to play more than simply an advisory role in the formulation of federal/state spending priorities. Yet, the precise dimension of the council's responsibilities were not made clear in the legislation. Since the original HEW regulations failed to deal with this matter, each state was largely left to its own devices to determine the working relationship between its council and designated state agency. As a result, the various states evolved quite different patterns of agency/council interaction - varying from states in which the council was almost totally independent of the administering state agency to states where the council served as simply an advisory body to the state agency.

The 1975 amendments to the Act (P.L. 94-103) attempted to distinguish between council and agency roles. In essense, the revised Act assigned responsibilities for day-to-day administration of the program, including the awarding of grant funds, to the state agency and focused the council's activities on system-wide advocacy, comprehensive planning, supervising the development of the state plan and evaluating the state's overall efforts on behalf of the developmentally disabled. One of the key elements in this realignment of council/agency responsibilities was the requirement that the agency prepare a "design for implementation" - i.e., a detailed plan, consonent with council-identified needs and spending priorities, for using the state's annual allotment under the DDSA program.

While P.L. 94-103 had succeeded in clarifying some of the most pronounced problems in council/agency relationships, the goals and activities of many councils are still quite different from those of the designated state agency and vis-a-versa. As indicated earlier, the Rogers bill would address this problem by focusing a large share of available federal dollars on a limited number of service priority areas. However, the proposed language does not include explicit language spelling out the role relationship of the council and the designated state agency. Section 137(b) lists the functions of the State Planning Council. But, nowhere in the bill can we find a parallel list of the functions and responsibilities of the state agency designated to administer the program. By inference, it appears that the bill's drafters intend that the designated state agency: (a) prepare and submit the state plan called for under Section 133, including the detailed plan for addressing the state's selected priority service areas (Section 133(b)(4)(A)(ii)); (b) disburse all federal funds allocated to the state under Section 131; and (c) generally assure that the DD formula grant program is efficiently and effectively managed.

We recommend that the Subcommittee insert a new section in the Rogers bill spelling out the duties and responsibilities of the designated state agency, including those listed above.

In addition, we think the Subcommittee should eliminate Section 133(b) and modify Section 133(b)(1)(B) and other relevant subsections of the bill to make it clear that the Governor must designate a single state agency to administer DD formula grant funds. This provision, which allows for the designation of one or more agencies to administer formula grant monies, was included in the original 1970 Act. To the best of our knowledge no state or territory has ever utilized this language as it was originally intended - i.e., to divide the state's allotment according to the programmatic expertise of the various state agencies (e.g., mental health/mental retardation; vocational rehabilitation, education; transportation, etc.), based on each agency's relative responsibilities for serving the target population. A few states have divided responsibility along functional lines (e.g., planning, construction and service), but, by and large, most states (48 in FY 1978) and territories (all 6 in FY 1978) have elected to designate a single state agency. Given the limited amount of funds available, both now and in the foreseeable future, we believe this is the only practical approach to efficiently and effectively managing the program.

5. Evaluating the Impact of the Program

The lack of a clear set of national program objectives combined with the strong focus on state level goal setting has made it extremely difficult to evaluate the impact of the Developmental Disabilities formula grant program. Since, as indicated earlier, the fundamental purpose of the program is to influence the quality and scope of services rendered to developmentally disabled persons through a variety of human service systems, traditional measures of the effectiveness of grant-in-aid programs (e.g., number of clients served, percentage of estimated needs met, number of individuals cured, rehabilitated, graduated, etc.) are almost meaningless. How does one objectively measure the effectiveness of a council's efforts to coordinate the activities of two or more major state agencies or the impact of a comprehensive state plan or a series of "seed money" grants on improving the accessibility of appropriate services to the target population. Can we determine if a particular council is serving as a catalytic change agent and forceful advocate for the interest of the developmental disabled within the state overall service network?

Under the best of circumstances, these and similar questions are difficult to answer. But, given the fact that, within broad statutory parameters, each state is permitted to establish its own goals and priorities, it becomes almost impossible to gain any general overall sense of the DD program's national impact.

We believe the Rogers bill would facilitate efforts to assess the national impact of the program by establishing specific priority service objectives. While, at least initially, the states would have flexibility to choose among the four service priority areas, it should be considerably easier to design a national strategy for determining the unmet needs of the target population and evaluating the impact of the DDSA program in meeting these needs.

6. Revising the Definition of Developmental Disabilities

Since the passage of the Developmental Disabilities Act in 1970, more time and attention has been devoted to debating which disabling conditions should and should not be included in the target population than any other single issue involving the legislation. Considering the fact that the term "developmental disabilities" is a legal/administrative construct rather than a clinical/diagnostic label, it is not surprising that there is considerable disagreement, even among experienced diagnosticians, concerning whether one etiological category or another meets the current criteria contained in the present law.

When this Subcommittee was considering the 1975 amendments, it inserted an amendment calling for an independent, objective study to establish "an appropriate basis for determining which disabilities should be included and which disabilities should be excluded from the definition . . ." (Section 301(b), P.L. 94-103). That study has now been completed and the Subcommittee will receive detailed testimony on the recommendations developed by the National Task Force on the Definition of Developmental Disabilities. Therefore, we will not review the Task Force's findings and conclusions here.

In general, we favor the functional approach to the definition proposed by both the majority and the minority members of the National Task Force. Clearly, the criteria for program eligibility should be based on the functional service needs of individuals with severe disabilities originating in childhood, rather than upon diagnostic labels. Such labels provide little practical guidance to the clinician or program administrator charged with the task of designing an effective service program.

The Association also supports the Task Force's emphasis on using DDSA resources to improve the lot of individuals with severe, lifelong disabilities. The original legislation was aimed at focusing public attention on persons considered too handicapped to benefit from mainstream human service programs. The proposed Task Force definition tends to underscore this point by requiring that the disabling condition significantly interfere with the individual's ability to engage in two or more major life functions.

Although we agree that the term developmental disabilities should be defined functionally, we also recognize that one must examine the practical ramification of expanding the number and types of disability groups currently eligible to receive program benefits. It is not simply a question of broadening the target group without comparable increases in federal authorization and appropriations levels, but whether the services and facilities currently available to new disability groups can and should be a logical extension of the emerging federal/state developmental disabilities service delivery system.

Under the proposed majority definition developed by the Task Force our understanding is that severely mentally ill children and adolescents would be considered part of the target population. While we recognized that this is an underserved group, it is also true that most states are currently attempting to address the problems of mentally ill children through their state mental health system. In fact, the federally supported Community Mental Health Centers are required by law, to provide a full range of diagnostic, evaluation and treatment services to mentally ill children. Although we support the expansion of federal aid for childhood mental health programs, the Association can see little rationale for expanding the definition of a developmental disability to cover such conditions. Not only would the already limited federal DD dollars have to be spread even thinner, but the repercussions, both fiscally and organizationally, at the state level would be difficult to rationalize.

On balance, then, the Association recommends that the Subcommittee proceed with great care before approving any significant expansion in the current statutory definition. A completely functional definition may be a worthy objective; however, given the yawning gaps in services to the disability groups currently covered and the differences in the service needs and delivery systems of groups who would be added under the Task Force's majority definition, we simply see no practical way to avoid drawing some categorical parameters around program eligibility.

However, should the Subcommittee decide to eliminate from the statutory definition all reference to specific diagnostic categories, then we would suggest that the age of onset of the disability be lowered to 6 or, at most 12, (rather than 22, as in the current definition), or 22, as in the Task Force's proposed definition. Such action would: (a) give greater assurance that the program would focus on the most severely handicapped children whose disabilities are generally demonstrable at a much earlier age; and (b) minimize the growth in the target population since cases of childhood mental illness often do not occur until the adolescent years.

7. . Revising the Mandate for University Affiliated Programs

The Association is generally pleased with the revised language authorizing grants for university affiliated programs (Section 121). The new statutory definition of a UAP would be a significant improvement over the current definition. We especially like the clear recognition that interdisciplinary training is a major mission of such university centers.

The Association believes, however, that the statutory goals of the university affiliated program should be more closely related to the general aims and objectives of the basic federal-state formula grant program. To achieve this purpose, NASMRPD recommends that Section 121(b) be amended to require that, after October 1, 19[illegible], priority be given to grants which would significantly assist state councils and designated state agencies to achieve the priority service objectives established under Section 133(b)(4)(ii).

* * * * * * * * *

In summary, we strongly endorse the basic approach of the Rogers bill and suggest that the Subcommittee consider the modifications discussed above when it marks up the legislation. As state officials responsible for the delivery of services to this target population, we are acutely aware of the existing gaps in services and recognize that increased federal assistance and leadership through the Developmental Disabilities program is one essential ingredient in closing these gaps.

We appreciate this opportunity to share the Association's views with the Subcommittee. Your past efforts to eliminate barriers to the full participation of developmentally disabled citizens in our society are deeply appreciated by the Association's members. For our part, we pledge our full support and cooperation as you consider legislation to extend and amend the Developmental Disabilities Act.

Mr. Rogers. Thank you, commissioner, for a most helpful statement. Mr. Carter?

Mr. Carter. I want to compliment the gentleman on what he has said. I know that is the way we have proceeded in the past 4 or 5 years; plans have been changed each year as we have gone along.

Mr. Chairman, it was either poor planning——

Mr. Thorne. Well, planning for planning's sake means in the sense that you have to change it very year because you have to come up with something different if you are doing your job. As a consequence, what happens is that you change plans but nothing happens in he meantime because nothing is implemented effectively to change services.

Mr. Carter. If you say "plan and then implement it," I would agree with that. But I do not think we need to have a different plan each year.

Mr. Thorne. I do not think so either, but that is what happens.

Mr. Carter. We get into the issue of special planners and I do not know whether it is good to have them or not. I think, perhaps, they should be in another position.

Thank you, Mr. Chairman.

Mr. Rogers. Dr. Ganser?

STATEMENT OF LEONARD GANSER, M.D.

Dr. Ganser. Thank you, Mr. Chairman. I have with me Jayn Wittenmyer who is the executive director of the Wisconsin Developmental Disabilities Council and Harry Schnibbe, who is the executive director of the National Association of Mental Health Directors.

Mr. Rogers. We are glad to have you, gentlemen.

Dr. Ganser. I am speaking for the National Association of State Mental Health Program Director [see p. 431]. Our association was involved in the initial legislation, in developing the initial legislation, and with your strong support, strong support of this committee.

We felt that the concept behind that legislation was sound and we are extremely enthusiastic about it. We do have a substantial interest in the legislation because in the majority of states, the implementing agency is either a mental health agency or a human service agency and to a large extent also, the residential beds in most of the States are the responsibility of mental health programs.

The association endorses the thrust of H.R. 11764 quite strongly. We do have some reservations about it and I will mention them later. We think the strong support is important because there are parts of it that do continue to reenforce the original concept of the developmental disabilities bill.

Certainly the strengthening of the council's capacity to review other State plans, the professional assessment and evaluation section, makes it possible for the council and the university affiliated facilities to work more closely together and the strengthening of the protection and advocacy system is important.

We see these as especially important because they do follow through on the original objectives which we think are still sound. We do believe there are some radical departures that differ from the original objectives.

The current legislation has been in effect now for sveral years. The original objectives are difficult to accomplish. The gap filling, the coordinating kinds of objectives are very difficult.

As a matter of fact, one of the problems that the States have with those kinds of objectives is that the Federal agencies do not follow through on them very well. There is little coordination at this level of those kinds of things. Therefore, the onus does fall on the States and local agencies to bring that coordination together.

I think the DD legislation has been a good example of legislation that encourages support and builds on that. I think the seed has been sown. I think there have been accomplishments, but I think there needs to be additional planning for further accomplishments.

The original intent of the act to provide States the opportunity to do their State planning, to determine their priorities, to determine allocation of resources, and to develop options between implementing gap-filling direct services versus planning, coordinating, influencing activities is very important and we believe should be strengthened and continued.

The use of existing services affecting people with developmental disabilities, the generic services, is an extremely important concept. Some people might refer to it as mainstreaming, keeping them in the general stream or system of services. If one does not do that and if one begins to fund the services to the developmentally disabled as a separate categorical kind of thing, one develops what I have often referred to as the waste basket phenomena.

Everybody says, "They do not belong to us, they belong over there." There is a tendency then to begin denial of services because there is another source of funding for those services.

We think that the radical departure from that initial concept is involved in the provision in section 133, the provision of priority services, and also in the matter of the 70 percent and 30 percent split of money in services versus planning.

So, we would suggest that this provision starting on page 24, line 20, and going through line 16 on page 28, be stricken from the bill. The states and territories do have very different conditions and needs for services. Federal legislation that takes away the opportunity for flexibility does not help them meet those individual kinds of priorities.

You did hear some testimony yesterday from Representative Mary Lou Munts from Wisconsin which defined, I think, some of the unique things that have happened in Wisconsin in the gap filling and the planning and the involvement of other kinds of services and I want to add to those.

When I am through if Jayn Wittenmyer would like to add a couple she thinks would be of interest to you, I will ask her to do that.

This flexibility that is present in the present law is what makes the small amount of money that comes into a State for this purpose available kind of thing and results in substantial increase in the utilization of both State money and other Federal money to provide services to the needs people.

We think in looking at the current legislation that if one is even to think about the concept of national priorities, we think that it is necessary to look at how those priorities were arrived at. I have a set of questions in my material and I merely want to say that those are questions that I think need to be raised as to how those priorities wer selected.

I think all of them are excellent. They are excellent areas where service needs to be improved. But I think it is important to note how they were selected, as an expression of what the needs are in all of the states and not necessarily just in a few States but in all of the States. I think that is a serious matter in trying to define those four priorities in Federal legislation.

I just want to make one comment about the definition of Devel-Disab. We feel strongly that the definition should continue as it is, that there may be a time when it should be changed but at the present, the provision of services to this group still has been identified as an important matter. It would be unfortunate to dilute that now and not follow through with the intent.

[Testimony resumes on p. 438.]

[Dr. Ganser's prepared statement follows:]

STATEMENT OF:

LEONARD GANSER, M.D.
ADMINISTRATOR
DIVISION OF COMMUNITY SERVICES
DEPARTMENT OF HEALTH & SOCIAL SERVICES
STATE OF WISCONSIN

ON BEHALF OF: NATIONAL ASSOCIATION OF STATE MENTAL HEALTH PROGRAM DIRECTORS

DR. GANSER IS CHAIRMAN OF THE TASK FORCE ON
DEVELOPMENTAL DISABILITIES OF THE NASMHPD
AND SERVED AS PAST PRESIDENT
OF NASMHPD 1968 - 1969

Mr. Chairman: The State Mental Health Directors participated in the first drafting of the concepts that led, with your encouragement and support, to the original Developmental Disabilities Act in the 91st Congress.

I have served as a witness before this committee on a number of occasions on behalf of the state government mental disabilities agencies, and I am happy to appear before you once again in support of extension of the Developmental Disabilities Act.

* * *

The State Mental Health Agencies have a substantial interest in this legislation, Mr. Chairman, because in 22 states the "DD" program is located organizationally in the State Mental Health Department.

Also, in 29 states the Mental Health Department has administrative responsibility for the mental retardation program, accounting for 51.9 percent of all inpatient MR beds in state government programs.

* * *

Our Association endorses in general the bill (H.R. 11764) introduced by you and Mr. Carter.

We do have some reservations about some provisions in the bill which, hopefully, might be resolved through our discussions with you this morning

We are inclined toward strong support of H.R. 11764 because, for the most part, it continues and reinforces the original intent of the developmental disabilities concept:

- An example of this reinforcement is your new Section 137 (b)(3) on page 29 which strengthens the Council's role in prior review of other state plans that have responsibility to persons who are developmentally disabled.

- Another example of your reinforcement of the original concept is Section 11 amending Section 133 of the Act, paragraph (6) (on page 27 of the bill) relating to professional assessment and evaluation systems. This will allow the Developmental Disabilities Councils and University Affiliated Programs to work in real synchrony.

- We also see as encouraging your strengthening of the Protection and Advocacy system, which establishes a "Bill of Rights" for Developmental Disabilities and a mechanism to implement it.

The state mental health agencies see H.R. 11764 as substantially furthering the objectives of the original Developmental Disabilities concept.

There are, however, some rather radical and surprising departures from the principles propounded by this Subcommittee when it developed the original Act, and we are both concerned about how or why these departures originated and disturbed over the possibility that they will shatter the unique (and largely successful) "coordinating and influencing" nature of the present program (which is only now beginning to grow and capture the imagination of public and private leadership).

* * *

Before discussing the section of H.R. 11764 that disturbs us, let's review what was the concept behind the original act that came out of this committee in the 91st Congress.

A principle on which the original Developmental Disabilities Act was structured was confidance that the diversity of the American system is one of its great strengths.

Thus it was the assumption of this Committee, and the Congress and the many organizations who helped frame and implement the Developmental Disabilities Act, that services to the developmentally disabled would best flourish through a system that took advantage of the sense of diversity and encouraged flexibility in:

- state planning
- determination of priorities
- allocation of resources
- options between implementing gap-filling direct services VS planning, coordinating and influencing activities.

* * *

We are now confronted with what must be considered a rather radical departure from the original assumptions of this committee and the U.S. Congress.

The state government mental health agencies are especially concerned about the change in direction of philosophy inherent in your amendment of Subsection (b) of Section 133, which adds a new "(4)- Provision of Priority Services" (page 24, line 20 of H.R. 11764).

We respectfully recommend that this provision, starting on page 24, line 20 and going through line 16 on page 26, be stricken from the bill. (Also to be deleted: the section defining "Priority Services", starting on p. 5, line 15 thru line 8 on p. 7.)

The states and territories represent disparate conditions and needs for services.

Federal legislation that would impose national priorities, set a percentage for allocation of resources, and mandate direct services, would destroy flexibility and risk binding the states inappropriately in a straight-jacket.

Perhaps I can best amplify on our position by describing some of the successful pioneer efforts under our own DD system in Wisconsin which most likely would never have occurred without the stimulating impetus from the federal Developmental Disabilities Act.

In Wisconsin, coordination in non-traditional ways has convinced other public agencies that they should be aware of, and involved in, DD services within their own delivery systems.

Through the activities of the Wisconsin DD Council significant progress has been made . . . . .

(1) in advocating legislative changes in: zoning; less driving restrictions for persons with disabilities; transportation; lead content in ceramic glaze and genetic intervention

(2) in influencing service dollars from H.U.D.; CETA; Transportation, etc.

(3) in promoting awareness of individuals who are developmentally disabled and are caught-up in the criminal justice system; an impact has been made on the need for knowledge and sensitivity in the courts, probation and parole and generic community services (including in-service-training and protection)

(4) in promoting within the Department of Natural Resources work sites and accessibility to the park system

(5) in sensitizing the community and professionals around the specific needs of minority persons who are developmentally disabled

• • •

Those 5 examples of the types of progress made in Wisconsin, Mr. Chairman, are typical of most of the states.

Those examples are essentially what much of the DD Act is about.

It is about flexibility in planning, priority-setting, resource allocation and options to provide direct services or provide coordination and influencing of services.

We feel that your new Section on page 24: "Provision of Priority Services", changes the whole nature and thrust of the original concept.

For this reason we recommend its deletion from H.R. 11764.

In considering our recommendation that the "Priority Services" section be deleted, the Subcommittee may want to review for background purposes several questions that should be satisfactorily answered before final judgment on that Section is rendered.

There are five (5) questions the state government mental health agencies themselves do not have satisfactory answers for, and we, as much as we presume you will be, are concerned about receiving adequate responses to them.

They are:

(1) On what basis was it determined that there should be a priority system?

(2) How was it decided that there should be only four priorities?

(3) How were the four priorities agreed upon?

(4) Was a needs assessment conducted?

(5) How was the decision arrived at to allocate only to direct services as opposed to using funds to impact on other resources? For example, Title XX, Title 19, H.U.D., Transportation, etc.

* * *

In regard the "definition" issue, Mr. Chairman, we support the definition in your bill.

The impact of change in definition would require massive revisions in states' legislation and would further require substantial increases in funding to meet the minimum needs of all persons to be included in a new generic definition.

Clarification of other federal legislation would assist in providing services to other handicapping conditions, for example, Title XX, for physically impaired. Many of the other handicapping condition would require special services which are different from those rendered to persons who are developmentally disabled.

* * *

In summation, Mr. Chariman, the state government mental health agencies support your efforts to extend and improve the federal Developmental Disabilities program, and we commend you and Mr. Carter and this Subcommittee for your extraordinary achievements on behalf of the mentally disabled.

We strongly recommend that the section on "Provision of Priority Services" be removed from the bill as destructive of the spirit and intent of your original legislation.

Otherwise we endorse H.R. 11764.

Thank you Mr. Chariman for your courtesy in hearing us today.

Mr. Rogers. Thank you, Dr. Ganser, for a helpful statement.

Ms. Wittenmyer. I think one of the things that Dr. Ganser suggested is that Wisconsin is one of the States putting 100 percent of their Federal dollars in planning and coordination activities. Some of the unique kinds of things is some dollars that were gotten from the whole sale tax credit program for people living in group homes, which is around $100,000 for the first try.

Another area is in the division of correction funding positions to look at the correction system, doing inservice training for the staff, trying to look at the kind of residential facilities for those people, what kind of protection needed within the correction system to protect developmentally disabled from other people in the system. We do have lots of examples.

Mr. Rogers. Thank you.

Mr. Schnibbe, do you want to make a comment?

Mr. Schnibbe. I do not think I have any comment after which I will proceed to talk for 10 minutes.

No, I think I would want to emphasize to you that Dr. Ganser's statement is in the process of being cleared by the Governors. I cannot say right now that the National Governors Association totally endorses it, but they are in the process of reviewing it and I hope in the course of the next few days I can say to you it has been cleared by the Governors. We are speaking for the Governors Association.

We reemphasize the fact that the State mental health agencies have administrative responsibilities for 56 percent of the MR beds, plus 22 of the States have the DD program lodged in those agencies.

So, what you are hearing today is a rather emphatic statement of a continuing and there is almost unanimity among the people who have cooperated in the development of this statement, unanimity in support of maintaining the program the way you originally conceived it when it first came along.

What you are proposing now in your bill, of course, is a radical change in the nature. The nature of the thing is to generate services and fund programs through a relatively modest amount of money.

A number of mental health commissioners have said to me maybe we could buy this priority services thing if Mr. Rogers, Senator Kennedy, and the Congress would increase the funding about 10 times. Then you have money to put into services. But without that kind of increase in appropriations, which you people are not ready to advocate, I suppose, then this kind of program that you originally came up with, which is to use these resources and develop other resources around the state the way Wisconsin has done, the way a number of states have done, through other Federal programs, other State programs, is the most effective way to run this program.

So, I think unless there is a substantial increase in funding for service, then this program is going to fail. This is the message we get from the States.

Mr. Rogers. Thank you.

Dr. Carter?

Mr. Carter. Thank you, Mr. Chairman.

I was particularly impressed, Dr. Ganser, with your statement that you have gone into the prison system to find what mental disabilities cause people to be there.

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Dr. Ganser. Yes.

Mr. Carter. I want to compliment you on that. Wht did you find?

Dr. Ganser. When we started this the prison system, the corrections system, stated as a matter of fact that they did not have any developmentally disabled people in their system because they would have been ruled out at the time of the court hearing as being noncompetent. I think that was about the level of their understanding of developmental disabilities, that they did not realize that they had many people within the system who were developmentally disabled and were either in local jails or were receiving services in a State correctional institution. They have now gone through a process of identifying the developmentally disabled in the prison system and are just now at the point of attempting to design specific programs for them so they can keep those individuals closer together and have special training programs more suitable to their needs.

Mr. Carter. There is one portion of the bill with which I believe you are in disagreement would like us to delete, starting on page 24, line 20.

Dr. Ganser. Right.

Mr. Carter. Why would you want that deleted?

Dr. Ganser. We would like to see that deleted because that is the part that has to do with the defining of priority services and also that has to do with the percentages of money designated for service.

We think that those should be left flexible for the States to operate as they set their priorities.

Mr. Carter. I think the Chairman will agree that we have tried it both ways, by the block grant method and by the categorical grant method. Whichever way we tried, the State people come back and ask for the other.

Is that correct, Mr. Chairman?

Mr. Rogers. That is right.

Mr. Schnibbe. Dr. Carter, what we are asking for is that the program be maintained the way it was originally conceived by your committee because we do not think the program has failed. We think it is succeeding all along. Now this is a new switch.

We are not asking for anything new. We are not asking you to change anything. You are the ones who are proposing to change it. We are saying give it a chance because it is a good program.

Mr. Carter. Thank you. I think it is a good program too. I have strongly supported it. My name is on it with the chairman's.

Mr. Rogers. I think on this point, as I understand it, Dr. Ganser wants a 100-percent flexibility on spending of funds. Commissioner Thorne said he saw the need for the establishment of priorities and maybe the requirement to go beyond planning to services.

Mr. Thorne. If you will look at what has happened throughout the country there has been great disenchantment with the developmental disability program from the point of view of mental retardation and State people responsible for operating the program.

The disenchantment has not come at all from the lack of interest and lack of involvement of people. What it has come from is the fact that you simply cannot approach a problem from a shotgun approach and be able to really solve it. You have to try to define what your goals are.

As long as you know you have limited resources, funds, and as long as you understand what the political scene is and the whole business of transition of power from one administration to the other, you have to get as much done as you possibly can within the time you have and you should not plan beyond your capability of seeing it through.

If you can focus on or put your efforts in that area and if the country in terms of this field can select some specific areas to focus on, I think we can benefit the developmentally disabled much more by the revelations we will receive from other States looking into the same set of problems.

Thus, we will really have something to hang our hat on rather than a whole proliferation of suggestions and plans and so forth that no one can put together into any meaningful continuity.

Mr. **Rogers**. Is it time now to begin to think more in terms of implementing the plan rather than simply continuing to develop plans?

Dr. **Ganser**. I understand very much the kind of observation that Mr. Thorne has made. I have a very capable young man who worked for me, who has direct responsibility for the development of direct service programs for the developmentally disabled. He is impatient with the fact that money is used to get title XX money to do other things because it means that some flexible money that would be in his program is not available to him.

My own responsibilities are such that I have responsibility for title XX, SSI outreach for youngsters, a number of other responsibilities. It seems to me that the real branching out and the growth of programs for the developmentally disabled need to be in those areas in addition to the specific services to the developmentally disabled or mentally retarded.

I think the payoff from the developmental disabilities legislation is just coming through there. I think we do need more money for service. We always need more money for service. We will never get enough.

In Wisconsin we are usually thinking of between $30 and $40 million of direct general purpose revenue going into services to the developmentally disabled, about $35 million of title IXX money, $12.5 million of title XX money, and $8 to $10 million of SSI money going into services in group homes.

If we were to add this $600,000 of money from this legislation, it would lose its effectiveness in getting those other services bought in.

Mr. **Rogers**. Thank you. Now let me ask you this.

Do you believe that the State councils should have the responsibility for plans and setting priorities or should it be the——

Dr. **Ganser**. It is my opinion that State councils should have the responsibility for setting the priorities and should be the major designer of the state plan.

Mr. **Rogers**. Do you share that view, Mr. Thorne?

Mr. **Thorne**. I would not share that exactly. I think certainly in terms of the proposed legislation, that ought to be very definitely stated. Certainly we have more hassle over that, who is what, and I think that is one of the problems that emerged over that question.

It depends a little bit on how broadly you define the problem. I do not believe that planning rests with any specific body in Government. I think that planning around some specific areas as outlined in the proposed legislation could be something that the council could put its teeth into.

But their finding is not going to stop, for example, my agency from planning because by statute we have responsibility for planning. Nor would it stop the other departments of the State that are dealing also with the developmentally disabled.

Coordination of planning might be a very important function of the council whereby those plans that are developed by various agencies, if the council could help pull those together——

Mr. **Rogers**. Should they have approval or disapproval?

Mr. **Thorne**. I think they should half signoff, but I do not think it should be totally with them. It should be a partnership relation.

One of the real things we have to work for is bringing the consumer and the "bureaucracy" together. Now, if we give one full option or the other, we are not going to bring them together that way. We have to find a way of making a team out of this. I think that is very important if the legislation can focus on the team effort, joint responsibility.

Ms. **Wittenmyer**. I concur that is what the council is, that is, bringing together the agencies and provider, consumer and the parent and they should be the priority maker because their role is coordination with all the other plans.

Mr. **Schnibbe**. Isn't that what you do in Wisconsin? In many of our States where the mental health department is involved, this is what happens, what Commissioner Thorne is saying is what happens.

Mr. **Rogers**. Dr. Carter?

Mr. **Carter**. I just want to say this, Mr. Chairman: Actually, of all our mental health programs, this is the most effective of all. We have comprehensive mental health programs of course, for alcoholics, for the mentally disturbed and for drug abusers. I regret that I do not see the effectivenesss in those areas, not nearly so as in this program. It has been extremely helpful.

Mr. **Schnibbe**. Because those other programs are direct services and you have all kinds of direct service problems in there, unless Congress is willing to put a half billion dollars in, the sums are never sufficient.

With this program, with the limited amount of money it is a coordinating and influencing program that coordinates other programs that brings them into the system.

Mr. **Carter**. I should say on this that we do not have nearly as much funding as we should. In other programs we have a lot more money.

Mr. **Schnibbe**. More headaches.

Mr. **Carter**. Yes, I regret to say this.

Mr. **Rogers**. Ms. Wittenmyer?

Ms. **Wittenmyer**. On the comment about our corrections system, our preliminary reports are showing about 10 percent of the adults in the State correctional facilities are developmentally disabled and between 12 and 15 percent of the juveniles. That is our preliminary finding at this point. So it is not a large percent, but it is people who need to have attention.

Mr. CARTER. If we could just find those children in our schools in the primary grades, we would be doing something to prevent all of this.

Ms. WITTENMYER. It is a very exciting area.

Mr. CARTER. I think it would be helpful.

Mr. GANSER. I will leave a copy of this report.

Mr. ROGERS. That will be helpful. Thank you so much.

Our next panel is Mr. Jon Rossman, the Governor's Commission on Advocacy for Persons With Developmental Disabilities, Department of Administration; Mr. Stephen B. Schnorf, director of advocacy, Governor's Planning Council on Developmental Disabilities, Springfield, Ill.; Ms. Dayle Bebee, executive director, Advocacy, Inc., Austin, Tex.; and Mr. Ethan B. Ellis, assistant project manager, Office of Advocacy for the Developmentally Disabled, Trenton, N.J.

We welcome each of you to the committee. Your statements will be made a part of the record in full. We will ask you to try to observe as much constraint in your testimony as far as time goes and you may proceed.

STATEMENTS OF ETHAN B. ELLIS, ON BEHALF OF STANLEY C. VAN NESS, PUBLIC ADVOCATE, STATE OF NEW JERSEY; JON ROSSMAN, DIRECTOR, GOVERNOR'S COMMISSION ON ADVOCACY FOR PERSONS WITH DEVELOPMENTAL DISABILITIES, FLORIDA; DAYLE BEBEE, EXECUTIVE DIRECTOR, ADVOCACY, INC.; AND STEPHEN B. SCHNORF, EXECUTIVE DIRECTOR, ILLINOIS DEVELOPMENTAL DISABILITIES ADVOCACY AUTHORITY

Mr. ELLIS. It is a pleasure to appear before you on behalf of Stanley C. Van Ness, public advocate of the State of New Jersey, to support H.R. 11764. Before I address the bill, let me briefly describe the history and accomplishments of New Jersey's Protection and Advocacy System for Developmentally Disable Individuals.

We began our program on December 12, 1976, when Governor Byrne approved our plan.

Since then, we have handled over 300 cases. Less than 10 of these have required litigation for successful resolution. One, known as "In the Matter of C.S." is currently before the New Jersey Supreme Court. It is the first right-to-treatment case brought on behalf of a mentally retared citizen in our State. In it, we are asking the court to find that individuals residing in institutions for the mentally retarded are entitled to a periodic judicial review of their status and treatment.

We have assisted the parents of 40 neurologically impaired and multiply handicapped children in convincing their country government to create a comprehensive special education system for all physically and mentally handicapped students in that country. That system will serve 150 children this fall and 500 next year.

We are currently assisting the State civil service commission in the revision of its regulations so as to assure the recruitment and hiring of more disabled employees. The commission has already created one special job title for the mentally handicapped and is preparing to recommend a statute to our State legislature which would allow it

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to create other job titles for which it could specifically recruit persons with mental retardation.

We received three additional Federal grants with the generous support and assistance of our New Jersey congressional delegation. That has allowed us to review the State's efforts at deinstitutionalization and provide assistance for the clients of the State's division of vocational rehabilitation. We are enthusiastic about our program. We are very proud of its accomplishments, and yet we have a long way to go. As our efforts become more widely publicized, the number of referrals we receive increases geometrically.

We served 200 people in our first year, and have served 100 in the first 3 months of this year. We believe that will continue to grow at that rate. The legislation you are considering today will help us greatly.

It authorizes funds which, if appropriated, would assure an orderly expansion of our capabilities to meet an expanding need. This is important, the need exists, and we must grow to meet it. However, it is equally important that our growth be orderly and well considered. Too often Federal programs, having met with a clearly defined need, are expanded too quickly to meet other needs which are less clearly perceived.

I should say parenthetically I was in the OEO programs in the sixties, and saw what happened on a grand scale, and I tell you, we tried to do too much too soon with too little, and we were all too late in the end, I guess, to fill that cliche out.

The legislation that you introduced and Dr. Carter cosponsored avoids this pitfall. Not only does it provide for an orderly expansion, but also requires an ongoing evaluation of the programs it supports, and of the needs of the people they are designed to serve. The legislation does several other things which give vital support to our efforts.

It retains the concept of developmental disabilities as a valid principal around which to organize services for a vulnerable population whose special needs have often been neglected. It extends the life of the State DD planning councils and UAF's. Others who appear before you today and yesterday have explained the value of these programs far more cogently and in more detail than I can or will. Let me say only this. If comprehensive coordinated services are to exist for developmentally disabled individuals and if trained staff are unavailable to provide them, advocacy on behalf of the people who need them will be that much more difficult. Except for the provision increasing the authorization for the advocacy systems, most of the changes this legislation brings about will have a more direct impact on the councils and on the UAF's than they will on us.

In these issues, we are merely interested spectators. We are quite interested, but we have been watching for 2 days now.

I for one would prefer to sit in the stands when these issues are debated and root for you to decide them wisely in a manner that is greatest benefit to the developmentally disabled, and I judge by what you have done so far that you will.

There are two issues which I must address, however, one because it more directly affects the P. & A. systems than may be apparent, and the other because the chairman has invited our comments.

The provision which restricts the amount of resources a State council may devote to planning and limits to four the service areas on which it may expend its remaining funds bothers us. We do not disagree with the concept in principle. However, advocacy is not one of the designated services, and 35 of the P. & A. systems now receive funds from these councils.

We are not suggesting that this is something that should be mandated, but we do suggest that this is an option that might be kept available to the States. They may not want to fund us directly, but they might want to fund related advocacy programs. When you introduced this bill, Chairman Rogers, you invited comments on the review of the definition authorized in the previous legislation. This will not affect our program in New Jersey very directly, so I would prefer you listen to other folks who do have an opinion there.

There is, however a related issue which is not directly before you, but which soon will be. Senator Jennings Randolph, in S.2600, is recommending the repeal of Public Law 94-103, and would substitute the severely handicapped for the developmentally disabled as the population we should serve.

I know that this concerns most of you. We have had questions from our Congresspeople back in New Jersey about it. It concerns us a great deal. Let me address those concerns now.

First, let me make it very clear that we oppose the repeal of Public Law 94-103. Over the last 7 years, the developmentally disabled have benefitted greatly from the programs established in the initial DD legislation, and continued and improved in Public Law 94-103. Until the unique needs of this vulnerable population are met, the developmentally disabled require the special attention of this Congress. The issue of expanding the constituency of the P. & A. systems is more complex. Philosophically and politically, we do not oppose it.

In New Jersey, the Department of the Public Advocate was founded on the proposition that all citizens may require someone with authority to speak on their behalf at one time or another. Disabled or not, we are not competent always to defend ourselves in the face of the bureaucracy which was created in order to deliver services we all need.

However, the time for such an expansion has not yet come. Most of the P. & A. systems are less than 1 year old. They are just beginning to demonstrate their ability to serve the developmentally disabled. Thirty-five of them are established as private, nonprofit corporations with boards of directors which reflect their current DD clientele. To require them to reorganize so abruptly, so early in their organizational lives will disrupt the orderly delivery of the advocacy services they are just beginning to provide so effectively. The time for such an expansion will come, perhaps toward the end of the life of this legislation.

When it does, that expansion should be adequately funded. S. 2600 authorizes no more funds to serve a greatly expanded clientele than H.R. 11764 does for fiscal year 1980. Such an expansion also should be very carefully planned. There are a variety of protection systems for the disabled now in place, some of them generated by the Rehab

Act of 1973, and I think in order to develp a system for a broader constituency, that fact should be taken into account, and a system should be designed that is coordinated with the other efforts generated by Federal legislation to protect this expanded clientele.

Finally, the needs of the developmentally disabled for advocacy services should be explicity recognized. It has been argued that the developmentally disabled have this greater need because they cannot speak on their own behalf. This is true. However, it is an even more persuasive argument which is less commonly made, perhaps because what it says about the rest of us by implication bothers us. It is this. Because there are deficits in intellect or communication, it is harder to represent the developmentally disabled and to advocate on their behalf.

Lawyers I have talked to—and I am not an attorney myself—complain that you have to make decisions about your clients that make you uncomfortable in that profession, and they suggest that if one had a choice between representing a client who could make their needs known easily and representing this population, their tendency and their desire would be to represent those who were not developmentally disabled.

In closing, let me commend the sponsors of the legislation for introducing it, and the subcommittee for acting on it so promptly. Thank you.

[Testimony resumes on p. 453.]

[Mr. Ellis' prepared statement follows:]

STATEMENT OF
ETHAN B. ELLIS,
ASSISTANT PROJECT MANAGER,
OFFICE OF ADVOCACY FOR THE DEVELOPMENTALLY DISABLED,
DEPARTMENT OF THE PUBLIC ADVOCATE

BEFORE THE
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT,
UNITED STATES HOUSE OF REPRESENTATIVES

APRIL 5, 1978

Mr. Chairman and Members of the Committee, it is a pleasure to appear before you on behalf of Stanley C. Van Ness, Public Advocate of the State of New Jersey, to support H.R. 11764. Before I address the bill, let me briefly describe the history and accomplishments of New Jersey's Protection and Advocacy System for developmentally disabled individuals.

On the advice of the New Jersey DD Planning Council, Governor Brendan Byrne ordered that our program be established in the Department of the Public Advocate. (This cabinet-level agency is unique to New Jersey. It was created to protect the interests of private citizens in the face of a growing bureaucracy. The Public Advocate is empowered to bring legal action against other cabinet officers when these interests are jeopardized or neglected and no other course of action proves effective.) The Office of Advocacy for the Developmentally Disabled was formally opened on December 12, 1976, when the Governor approved its first State Plan.

Since then, we have handled over 300 cases. Less than ten of these have required litigation for successful resolution. One, known as In the Matter of C.S., is currently before the New Jersey Supreme Court. It is the first right-to-treatment case brought on behalf of a mentally retarded citizen in our State. In it, we are asking the Court to find that individuals residing in institutions for the mentally retarded are entitled to a periodic judicial review of their status and treatment.

We have assisted the parents of forty neurologically impaired and multiply handicapped children in convincing their Freeholders to create a comprehensive special education system for all physically and mentally handicapped students in their county. This system will serve 150 children this fall. That number will exceed 300 next year.

We are currently assisting the State Civil Service Commission in the revision of its regulations so as to assure the recruitment and hiring of more disabled employees. It has already created one special job title for the mentally handicapped. It is preparing to recommend a statute to our State legislature which would allow it to create other job titles for which it could specifically recruit persons with mental retardation.

With the support of three additional grants from various Federal offices obtained with the generous help and encouragement of members of the New Jersey Congressional delegation, our staff has expanded from three to nine professional employees. This has enabled us to monitor the State's efforts to seek less restrictive community placements for individuals currently residing in institutions for the mentally retarded. With this additional staff, we are also able to assure clients of the State Division of Vocational Rehabilitation that they receive adequate and appropriate services.

We are enthusiastic about our program. We are very proud of its accomplishments. And yet, we have barely scratched the surface. As our efforts become more widely publicized, the number of referrals we receive increases geometrically. We responded to 200 cases last year; we have already responded to more than 100 in the first three months of this year.

The legislation you are considering today, H.R. 11764, would help us greatly. It authorizes funds which, if appropriated, would assure an orderly expansion of our capabilities to meet an expanding need. This is important. The need exists and we must grow to meet it. However, it is equally important that our growth is orderly and well considered. Too often, Federal programs, having met a clearly defined need, are expanded too quickly to meet other needs which are less clearly perceived. As a result, their initial benefits are diminished or destroyed and clients, service providers, and legislators alike become disillusioned with them.

The legislation introduced by Mr. Rogers and cosponsored by Mr. Carter avoids this pitfall. Not only does it provide for an orderly expansion, it also requires an ongoing evaluation of the programs it supports and the needs of the people they are designed to serve.

This legislation does several other things which give vital support to our efforts. It retains the concept of developmental disabilities as a valid principle around which to organize services for a vulnerable population whose special needs have often been neglected.

It extends the life of state DD Planning Councils to coordinate existing services for this population and to plan for and implement the more comprehensive service network they need. It continues funding for University Affiliated Programs to research the causes of developmental disabilities, to develop new techniques for their treatment, and to provide training to staff in the use of these treatment techniques.

Others who have appeared before you yesterday and today have explained the value of state DD Planning Councils and University Affiliated Programs more cogently and in more detail than I can. Let me add only this: If comprehensive, coordinated services do not exist for developmentally disabled individuals and if trained staff are unavailable to provide them, our advocacy on behalf of people who need them will be that much more difficult.

Except for the provision increasing the authorization for the protection and advocacy systems, most of the changes this legislation would bring about will have a more direct impact on the DD Planning Councils and on University Affiliated Programs than they will on us. On these issues, we are merely interested spectators. I, for one, would prefer to sit in the stands when these issues are debated and root for you to decide them wisely in a manner which is of greatest benefit to developmentally disabled persons.

There are two issues which I must address, however: one, because it more directly affects P&A Systems than may be apparent; the other, because the Chairman has invited our comments.

The provision which restricts the amount of resources a State Council may devote to planning and limits to four the service areas on which it may expand its remaining funds bothers us. We do not disagree with this concept in principle. However, advocacy is not one of the designated services. In New Jersey, we have enjoyed the benefit of a sizeable grant from the State Council and have undertaken a number of joint projects with it. It is our understanding that a similar relationship exists in most of the other states. Therefore, we recommend that advocacy be included as a fifth designated service area so that Councils can retain their options to support either the P&A Systems themselves or other related services.

When he introduced H.R. 11764, Chairman Rogers invited comments on the review of the definition of developmental disability authorized in Public Law 94-103. While the changes contained in the majority and minority reports of the ABT Commission will effect the providers of generic services and may effect the other P&A Systems,, they will not have a great impact on us in New Jersey. Therefore, we suggest that on this issue you be guided by the testimony of our colleagues from Florida, Illinois, and Texas, and others who appear before you.

There is, however, a related issue which is not directly before you now but soon will be. Senator Jennings Randolph, in S. 2600, is recommending the repeal of Public Law 94-103 and would substitute the severely handicapped for the developmentally disabled as the population to be served by the P&A Systems.

I know that this issue concerns most of you. Back home in New Jersey, Mr. Maguire's staff has begun to ask some insightful questions about its impact on the disabled community. It concerns us, too. Let me address those concerns directly.

First, let me make it very clear that we oppose the repeal of Public Law 94-103. Over the last seven years, the developmentally disabled have benefited greatly from the programs established in the initial developmental disabilities legislation and continued and improved by Public Law 94-103. Until the unique needs of this vulnerable population are met, the developmentally disabled require the special attention of this Congress.

The issue of expanding the constituency of the P&A Systems is more complex. Philosophically and politically, we do not oppose it. In New Jersey, the Department of the Public Advocate was founded on the proposition that all citizens may require someone with authority to speak on their behalf at one time or another.

However, the time for such an expansion has not yet come. Most of the P&A Systems are less than a year old. They are just beginning to demonstrate their ability to serve the developmentally disabled. Thirty-one of them are established as private, nonprofit corporations with boards of directors which reflect their current developmentally disabled clientele.

To require them to reorganize so abruptly so early in their organizational lives will disrupt the orderly delivery of the advocacy services they are just beginning to provide so effectively.

The time for such an expansion will come, perhaps, toward the end of the life of the legislation you are considering here today. When it does, that expansion should be adequately funded. S. 2600 authorizes no more funds to serve a greatly expanded clientele than H.R. 11764 does for fiscal year 1980. Such an expansion should also be planned for carefully.

Finally, the greater need of the developmentally disabled for advocacy services should be explicitly recognized. It has been argued that the developmentally disabled have this greater need because they cannot speak on their own behalf. This is true. However, there is an even more persuasive argument which is less commonly made, perhaps because of what it says about the rest of us by implication. It is this. Because of their deficits in intellect or communication, it is harder to represent the developmentally disabled and advocate on their behalf. As a result, in any expanded P&A System, their interests will tend to be neglected. Therefore, one prerequisite for expanding the current P&A Systems must be the guarantee of such services to the developmentally disabled.

In closing, let me commend the sponsors of this legislation for introducing it and the subcommittee for acting on it so promptly. Thank you.

Mr. ROGERS. Thank you, Mr. Ellis, for an excellent statement. We are very grateful to you for being here.

Mr. CARTER. Mr. Chairman, before I go, I would commend the gentleman on his statement also.

STATEMENT OF JON ROSSMAN

Mr. ROSSMAN. My name is Jon Rossman. I am the director of the Governor's Commission on Advocacy for Persons with Developmental Disabilities for the State of Florida.

Mr. ROGERS. We are glad to have you here from Florida.

Mr. ROSSMAN. I am glad to be with you here. We stand behind Mr. Ellis's statement wholeheartedly, and would like to briefly describe our experience in implementing the protection advocacy system, to demonstrate to you why we are in support of House bill 11764. Largely because as advocates for the developmentally disabled, we feel it is in their best interest. and then also with the interest of the protection advocacy systems themselves in mind, this bill creates increased funding with very little changes, and I am sure we are not the first people to come before you in support of that kind of legislation.

Section 113 has created a dramatic opportunity for Florida to expand its commitment to the rights of the developmentally disabled. The Florida Bill of Rights of Retarded Persons made Florida the first State in the Nation to affirm the rights of retarded individuals. Addressing widespread deprivations that had become common practice in the institutions, the Florida bill of rights held open the promise of dignity and appropriate care. In 1977, our legislature codified the philosophy of normalized services to be provided in the least restrictive environment, and expanded the protection of the Florida bill of rights to persons with cerebral palsy, autism, and epilepsy as well.

Since 1975, citizen committees have been functioning under legislative mandate throughout the State, monitoring the entire human services delivery system. These human rights advocacy committees are our first line of defense against abuse and neglect at the local level and are supported at the statewide level by a statewide human rights advocacy committee.

Our commission is made up of one-half the members of the statewide committee plus an additional group of individuals who represent the developmental disabilities, but not until the creation of the State protection advocacy system have developmentally disabled citizens had available to them a mechanism capable of pursuing administrative, legal, and other appropriate remedies.

Until now, violations of rights could be identified and pointed out to responsible authorities, but there was no place to go to pursue remedies if change was not gratuitously forthcoming. This had resulted in some overall movement toward long-range improvement at a reasonable pace, but no relief for individuals denied benefits or services to which they were presently entitled.

When the State began charging maintenance fees to parents of children in institutions, the P & A system stepped in to remind the

State of its responsibility to provide free, appropriated education to all children, including children institutionalized in retardation facilities, when in order to economize on a legislative mandate to provide involuntary admissions to State retardation institutions, the State agency sought to institute mass guardianship proceedings instead of pursuing the most costly voluntary procedures. Private lawyers with the support of the P. & A. system have filed suit to enjoin that State action.

We have cases now which we are working on, not necessarily in litigation, involving the use of strong psychotropic medications which have been administered to a 12-year-old girl in a State institution for pinching other institutionalized residents. We have another case involving a doctor who simply refused to examine a severely brain damaged child, and another case of a mother who refuses to be forced to institutionalize her son, whom she knows she can care for at at home, if only the services which are supposed to be provided do not get fouled up in bureaucratic delay and disinterest.

We have been fortunate to have been able to mobilize existing resources in the State of Florida in addition to the human rights advocacy committees to handle many of these cases. Our strategy has been case-by-case referrals and backup assistance. We are prepared to hire counsel when necessary. Next month we will bring together public defenders and legal service attorneys from every program throughout the State for a special developmental disabilities law seminar. The Florida bar, largely through the efforts of the P. & A. system, has demonstrated a very strong commitment by the establishment of a bar committee on the legal rights of mentally disabled and by a commitment to continuing legal education programs in this area.

Next year we anticipate to concentrate with equal intensity on developing and training non-lawyer-volunteer advocates. Finally, if financial resources are increased and become available to us, we must back up this entire system with regional centers with full-time staff support. The presence of existing statewide groups has allowed Florida to mobilize its protection advocacy system very quickly at a very low cost. We still have not chosen to hire a second professional. I am the only professional staff on the commission, and we have held in reserve a sizable sum for litigation expenses. In fact, we have only drawn upon the first quarter of our Federal appropriation. Yet this belies on impending confrontation with our limits. We have deliberately held back on widespread publicity in order not to raise too quickly expectations that we were not prepared to meet even with a high percentage of cases referred out to other agencies. We are finding it more and more difficult to follow up with the kind of backup support we would like to send along with a case before we refer it.

There is such an enormous variety of complex legal, social, medical, and economic problems involved in just this DD population that each case virtually requires us to start from scratch. It is for that reason that at this stage we are extremely concerned about expanding the definition beyond our capabilities.

Every month, we have seen an increased number of cases referred to us. Even if we could keep up with just the back-up assistance, there is a limit to the number of DD cases outside systems can absorb. What we still have no way of knowing is, if our training and development of nonlawyer advocates will relieve this burden or simply increase the number of cases which are identified as requiring the help of attorneys.

In addition, we know that there are major systemwide issues that we will have to address directly ourselves. If we began an extensive investigation on just one of these issues, we will very quickly exhaust all our fiscal resources and leave very little time for anything else.

H.R. 11764 provides us an opportunity to build on our experiences. Perhaps our largest source of expertise in dealing with the problems of the handicapped in education, habilitation, and institutions in the community is emerging out of the experience of these protection and advocacy systems, at least those systems that have had an opportunity because of the level of their funding to begin to deal with individual problems. A vast majority of the protection advocacy systems in our region, in Kentucky, Tennessee, Mississippi, Alabama, South Carolina, simply have not been able to gear up to the kind of involvement we have done in Florida. We need to bring all States at least to that level.

In many respects, the P. & A. systems are like the first airplane. If everyone who wanted to get a ride climbed on after the first flight, it would have never gotten off the ground again. Today, we have trans-Atlantic transports and so forth. The P. & A. system is a prototype of perhaps the most innovative concept in Federal legislation. It provides grassroots accountability for Federal programs and policies. We are very much in support and very grateful for this committee's efforts in giving us a change to get off the ground. Thank you.

Mr. Rogers. Thank you very much, Mr. Rossman, for an excellent statement.

Ms. Bebee?

STATEMENT OF DAYLE BEBEE

Ms. Bebee. Mr. Chairman, my name is Deyle Bebee. I am an attorney and the executive director of Advocacy, Inc. It is my pleasure to speak to you today in support of H.R. 11764.

Advocacy, Inc., is a nonprofit organization that is implementing a protection and advocacy system for the developmentally disabled in Texas. Governor Briscoe designated the State Bar of Texas, which had been the planning agency, to be responsible for the protection and advocacy system. The State Bar contracted with Advocacy, Inc. to actually implement the system. The corporation was created and chartered for the sole purpose of implementing the State P. & A. system. The corporation and the advocacy system have been in existence since October 1, 1977, with a staff of five attorneys and one nonattorney position.

We have an independent, 11-member board of directors, with the members appointed according to our bylaws in this manner: 6 by the State Bar of Texas, 1 by each of the four State consumer organizations, and 1 from our State DD planning council. The board determines our operating policies and helps us set our goals and priorities for the advocacy system. We are totally funded by HEW funds, with a total appropriation of $155,000. I believe I can truthfully say that we have become the source of technical expertise in our State in all the laws relating to the legal rights of the handicapped. All of the State agencies providing human services in Texas contact us and refer persons to us with those kinds of questions.

Our staff of five attorneys deliver direct services to the DD population and the service providers in these ways. I would like to mention to you also that since October 1, 6 months ago, we have handled a total of 335 contacts in our State. This is approximately five contacts per working day, and as Ethan mentioned to you, the number of contacts is rising geometrically. There has been almost a 300-percent increase between last quarter and this quarter. The three components of our protection and advocacy system are, first, education and training. We are doing the research, and studying all of the new Federal and State laws, Public Law 94–142 the Rehabilitation Act, and other legislation. We are developing written handout materials that we can then use in education and training sessions. Since we began, we have held over 38 education and training sessions, and we have reached an audience of over 4,500 people. Our second component is systems advocacy. In Texas, I served with a committee that wrote the Mentally Retarded Persons Act, which brought Texas into line with Florida in recognizing the legal rights of the mentally retarded. We have a new limited guardianship statute in Texas for the mentally retarded. We have been working very closely with our State mental health, mental retardation department in implementing that new legislation and in doing extensive review and comment and working on task forces that write the rules and regulations under both those acts.

We are extensively involved in our State in seeing to the implementation of Public Law 94–142. We are working very closely with our State education agency in raising issues about our State plan for special education, and in seeing to it that handicapped children are given the education that they deserve.

We are also planning to hold a statewide conference on how to implement 503 and 504 of the Vocational Rehabiltation Act by bringing in experts on how to come into compliance with those new provisions.

Our third component is legal and protective advocacy. We have a toll-free incoming WATS line where we take calls. We provide information about the law and legal rights of handicapped persons. We can make referrals, some referrals to the service delivery system, and we can provide technical assistance to developmentally disabled persons, their attorneys, and other advocates working on their behalf in administrative proceedings and legal proceedings. As an absolute last resort, we have the authority to file litigation on behalf of our own clients. We have not filed any lawsuits, but we are currently involved in some negotiations on education-related issues, which I expect probably will have to be litigated.

Our priority areas for involvement this first year were voted on by our board in October, and they are, one, the right to education. This is where we have had the greatest number of contacts in the State of

Texas. Two, employment rights. Three, rights of persons in institutions. Four, barriers to programs and services. Five, implementation of recent Texas legislation.

I join Mr. Ellis and Mr. Rossman in their support of continuing the concept of developmental disabilities and increasing the funding to the P. & A. system. I believe that the population currently defined as developmentally disabled have special needs for the voice and assistance of an advocate on their behalf, and while I have no philosophical disagreement with expanding services to other handicapped persons, I believe the DD population must continue to be a focus of the advocacy services.

I also believe that we must realistically look at the extremely broad mandate to the P. & A. systems and to the resources which are being given to the States to meet that mandate. As Public Law 94–103 currently States, the P. & A. systems must have the authority to pursue legal, administrative, and other appropriate remedies on behalf of DD persons. In Texas, we have approximately 200,000 to 400,000 developmentally disabled individuals scattered over a state that encompasses hundreds of thousands of square miles, with 12 State schools for the mentally retarded, 13 State hospitals, and 28 community mental health, mental retardation centers. We are attempting to meet that mandate with a staff of five persons, all located in Austin, and a budget of $155,000.

I have polled all of the other States in my region, Oklahoma, New Mexico, Arkansas, and Louisiana, and most of them are attempting to meet that mandate with a staff of one or two persons and $20,000 in funding. Most every State desperately needs the ability provided through adequate funding so that it can truly have statewide impact and be able to provide services to the total constituency, including minority persons and persons in rural areas.

I see two basic problems with changing and expanding the population to be served by the P. & A. systems. First there is the problem of the services that can be realistically rendered by the P. & A. system, and a related problem of outreach, and the publicity required to tell people about the P. & A. system. I speak for Texas, but we are not alone, when I say that we have not done an extensive outreach publicity campaign, because it is painfully obvious to us that we simply could not now handle the volume of responses that would be generated. If the population is to be increased, it is imperative that the dollars for staff and services be increased, or we will only succeed in raising the reasonable expectations of thousands of persons who qualify for P. & A. services, only to have those expectations dashed again because there is not enough staff to handle the requests for assistance.

The second problem we can identify with changing the population to the severely handicapped is that it is clear that the majority of those persons who meet that definition will probably be living in institutions. I fully recognize the significant needs of persons in institutions and the need for advocates to be able to attend to those needs. However, I believe we would have a difficult problem with accessing those clients. For example, the Texas P. & A. system is a private, nonprofit corporation, as are 34 other States. We do have the Federal mandate to advocate and protect the rights of the DD population, but we have no greater authority than any other person in the State of Texas or any other attorney to go into any institution in Texas. There is no State law giving us any additional or special authority to investigate institutions. Also, with a staff of attorneys, we cannot go into institutions to look for clients or solicit business, yet these are the very persons who will not be able to contact us. Without any additional authority, we will not be able, except in isolated instances where staff or family members contact us, to provide services to the institutional population.

Another quick point I would like to make is that the entire structure of the Texas P. & A. system, including our board of directors and bylaws, would have to be changed if the definition of our population were changed to the severely handicapped, since, as I mentioned to you earlier, our bylaws currently mandate a board of directors and services based on the DD structure. Most of the P. & A. systems are are less than 6 months into operation. Right now the most critical issue is lack of funding to meet the mandate of 94–103. It saddens me to report to you that a significant amount of staff time that should go into service delivery is being spent by necessity in seeking other funding sources to provide a minimum level of services.

In closing, I would like to say that before Congress changes the program, I believe we must have time for the P. & A. systems to learn how to deal with their responsibilities under the law and to learn how to be effective advocates for their constituencies, and I hope that Congress will recognize the tremendous need for additional funding. I am excited about my job and our program and the potential of the protection and advocacy concept, and I appreciate the support of the subcommittees and the Congress.

[Ms. Bebee's prepared statement follows:]

[Testimony resumes on p. 466.]

PREPARED REMARKS OF
DAYLE BEBEE,
EXECUTIVE DIRECTOR,
ADVOCACY, INCORPORATED

BEFORE THE
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT
UNITED STATES HOUSE OF REPRESENTATIVES

APRIL 5, 1978

I am Dayle Bebee, Executive Director of Advocacy, Incorporated. It is my pleasure to speak with you today in support of HR 11764.

Advocacy, Inc. is the non-profit corporation that is implementing the Protection & Advocacy System for the Developmentally Disabled, created pursuant to P.L. 94-103, in Texas. Governor Briscoe designated the State Bar of Texas, which had been the planning agency, to be the responsible agency. The State Bar contracted with Advocacy, Inc. to actually implement the system. The corporation was created and chartered for the sole purpose of implementing the state P & A system.

The corporation and the advocacy system have been in existence since October 1, 1977, with a staff of five attorneys and one non-attorney position that is currently vacant. We have an independent 11-member Board of Directors with the members appointed according to our By-Laws in this manner: six by the State Bar; one by each of the State DD consumer organizations. and one by the State DD Planning Council. This Board determines our operating policies and helps us set our goals and priorities for the advocacy system.

We are totally funded by HEW funds, with a total appropriation of $155,000 for fiscal year 1978.

I believe I can truthfully state that we have become the source of technical expertise in Texas with respect to the legal rights of the developmentally disabled. Since our beginning six months ago, the staff has responded to a total of 335 contacts; which is an average of five contacts per working day, and the rate of the contacts is rising dramatically each month.

Our staff delivers direct services to the DD population, families, and service-providers in these ways:

(1) Education & Training - we have been researching all of the recent federal and state law relaring to the handicapped, such as P.L. 94-142, The Vocational Rehabilitation Act of 1973, and a new Mentally Retarded Persons Act in Texas; we prepare written materials and handouts explaining the laws and the requirements for implementation; and we provide education and training by holding workshops, seminars, parent meetings, meetings with service-providers, and sessions with attorneys and judges. To date we have held thirty-eight education and training sessions, reaching a total audience of 4,500 persons.

(2) Systems Advocacy - we are involved in the legislative processes in Texas; for example, I assisted the committees in Texas writing the Mentally Retarded Persons Act and the Limited Guardianship statute for the mentally retarded; we also work closely with the state agencies responsible for implementing the laws to insure appropriate implementation, and we do extensive review and comment on proposed rules and regulations; we serve on task forces that prepare drafts of proposed rules. We have been very active in our state in working with our state education agency to come into compliance with the provisions of P.L. 94-142, and we are planning a major state-wide conference for service-providers on how to comply with the Section 503 and 504 Regulations of the Vocational Rehabilitation Act.

(3) Legal & Protective Advocacy - we have a toll-free WATS line; we provide information and answer direct questions; we make some referrals for services; we provide technical assistance to DD persons, their families, and other advocates in administrative procedures and in litigation; and, as a last resort, when we have attempted to resolve a particular problem in every way we think appropriate, we have the authority to file lawsuits on behalf of our own clients. This has not been done yet, but we are presently in the process of negotiating some situations

that will probably have to be litigated.

Our priority areas for involvement for this first year are: the right to education; employment rights; rights of persons in institutions; barriers to programs and services; and implementation of recent Texas legislation.

I join Mr. Ellis in his support of continuing the concept of developmental disabilities and of increasing the funding to the P & A systems. I believe that the population currently defined as developmentally disabled have special need for the voice and assistance of an advocate on their behalf, and while I do not have any philosophical disagreement with expanding services to other handicapped persons, I believe that the DD population must continue to be a focus of the advocacy services.

I also believe that we must realistically look at the extremely broad mandate to the P & A systems and to the resources which are being given to the states to meet that mandate. As P.L. 94-103 currently states, the P & A systems must have the authority to pursue legal, administrative and other appropriate remedies on behalf of developmentally disabled persons in the state. In Texas we have approximately 200,000-400,000 DD individuals scattered over a state that encompasses hundreds of thousands of square miles, with twelve state schools for the mentally retarded, thirteen state hospitals, and twenty-eight community mental health mental retardation centers. We are attempting to meet that mandate with a staff of five persons, all located in Austin, and total funds of $155,000. Most of the other states in Region VI are attempting to meet their responsibilities with a staff of one or two persons and $20,000 in funding.

Most every state desperately needs the ability, provided through adequate funding, to be able to regionalize the P & A system so that it can truly have statewide impact and be able to provide services to the total constituency, including minority persons and persons in rural areas.

I see two basic problems with changing and expanding the population to be served by the P & A systems, which is a concept that is being proposed in other legislation: First is the problem of the services that can realistically be rendered by the P & A system and the related problem of outreach and publicity required to advise people about the P & A system. I speak for Texas, but we are not alone, when I say that we have not done an extensive outreach-publicity campaign because it is painfully obvious to us that we simply could not now handle the volume of responses that would be generated from persons meeting the current definition of DD. If the population is to be increased, it is imperative that the dollars for staff and services be increased, or we will only succeed in raising the reasonable expectations of thousands of persons who qualify for P & A services only to have those expectations dashed again because there is not enough staff to handle the requests for assistance.

A second problem that we can identify with changing the population to the "severely handicapped" is that it appears that the majority of persons who meet that definition will probably be living in institutions. I fully recognize the significant needs of persons in institutions and of the need for advocates to be able to attend to those needs. However, I believe we would have a difficult problem with accessing those clients. For example, the Texas P & A system has been created as a non-profit corporation, as have about 34 other state systems. We have the federal mandate to advocate and protect the rights of the developmentally disabled, but we have no greater authority than any other citizen of Texas or than any other Texas attorney representing a client to go into any institution in Texas. There is no state law giving us any additional or special authority to investigate institutions, nor is there any in the federal law. Also, with a staff of attorneys, we are not able to go into institutions and seek out clients or "solicit business", as this is in violation of the Canons of Ethics. Yet, these are the very persons who will not be able to take their own action to contact us. Without any additional authority, we will not be able, except in isolated instances where staff or family members contact us, to provide services to the institutional populations that are the persons who would be defined as "severely handicapped". I also believe that there are many persons who are fortunate enough to be able to live in the community but who still have substantial needs for advocacy to assist them to get the community programs and services they need so that their futures are not limited to institutional settings.

For all of the above reasons, I support the minority definition of developmental disabilities. From my own experience, many people who call us and for whom we can and do deliver needed advocacy would not be able to meet the other proposed definitions, yet they must be able to access the advocacy system. Also, I can foresee ludicrous situations, again from my own experience, if we had to "diagnose" each person who contacts us for services to determine if that person meets a number of a given set of criteria in a definition. We have no way to make that kind of analysis on each person who contacts us and asks for advocacy services or assistance with legal problems.

Another quick point I would like to make is that the entire structure of the Texas P & A System, including our board of directors and By-Laws would have to be changed if the definition of our population were changed to the "severely handicapped", since, as I mentioned to you earlier, our system currently is based on a developmental disabilities structure. I am sure this applies to other state systems that are non-profit corporations.

Most of the P & A systems are less than six months into operation. Right now the most critical issue is lack of funding to meet the mandate of P.L. 94-103. It saddens me to report to you that significant amounts of staff time that should go into service-delivery in each state are being spent, by necessity, in seeking other funding sources to enable each system to provide a minimum level of P & A services.

In closing, I would like to say that before Congress changes the program, I believe we must have time for the P & A systems to learn how to deal with their responsibilities under the law and to learn how to be effective advocates for their constituents, and I hope Congress will recognize the tremendous need for additional funding to enable the state P & A systems to meet those responsibilities.

I am excited about my job and our program and about the potential of the protection and advocacy concept, and I appreciate the support of this Subcommittee and of Congress.

Mr. **Rogers.** Thank you very much. It has been an excellent statement.

The committee will stand in recess for 5 minutes. There is a vote.

[Brief recess.]

Mr. **Carter.** [presiding]. The meeting will come to order.

Mr. Schnorf, you are next.

STATEMENT OF STEPHEN B. SCHNORF

Mr. **Schnorf.** Thank you, Dr. Carter. I am Stephen Schnorf. I am the executive director of the Illinois Developmental Disabilities Advocacy Authority.

Some time in our advocacy role we become disenchanted with the bureaucracy of State agencies. I see that our own bureaucracy broke down and got the wrong job title to you on the information you have. I do work for the Illinois Developmental Disabilities Advocacy Authority, the agency created in Illinois to discharge the State's responsibility under section 113 of Public Law 94–103.

Illinois had made a substantial commitment to meet the public responsibility inherent in the protection and advocacy requirements of the Developmentally Disabled Assistance and Bill of Rights Act. This commitment includes a significant amount of State tax dollars. Our plan in Illinois, prepared by the Governor's Planning Council on Developmental Disabilities, with extensive community input, creates a citizen consumer-controlled, community-based advocacy service. Legal advocacy is provided through a consortium of legal assistance foundations throughout Illinois.

We provide some additional funding through those legal assistance foundations above and beyond the Federal funds they receive through the legal services corporation, in order to encourage and enable them to develop a specific expertise in developmental disabilities. That project has been operational for 2 months in Illinois.

To give the committee some idea of the types of activities they are becoming involved in, most recently they have successfully represented in an administrative hearing an epileptic person suspended and threatened with dismissal by the U.S. Postal Service after a seizure. The law project successfully pointed out to the U.S. Postal Service that that might be a rather flagrant violation of the person's guaranteed rights in this country, and is currently representing a child denied supplemental security income benefits by the Social Security Administration, in direct conflict with the Social Security Administration's own regulation. The child lives in a 24-hour-a-day, year round, residential facility for severely handicapped children, occasionally visits parents at home, and the Social Security Administration in its infinite wisdom has deemed that the child lives at home and that therefore the parents income should be counted in determining the child's eligibility for benefits. Those are just two examples of the approximately 20 cases that the law project is currently involved in after 2 months of operation.

Assistance to consumers and their representatives in pursuit of administrative and other nonlegal remedies is available through area advocacy projects operated by community groups under contract with our Advocacy Authority and through an ombudsman service operated by the Authority itself.

Again, as an example of the kinds of activities that we are involved in in those nonlegal areas, currently we are assisting a mother whose young daughter in a State-operated institution in Illinois has suffered some rather severe physical abuse and physical injury. We are assisting the mother in obtaining some immediate relief, transfer of the child from one unit to another.

Mr. CARTER. Is the child mentally retarded?

Mr. SCHNORF. Yes; the child is mentally retarded. We will continue to assist the mother in achieving her long-range desire, which is to get the child back closer to home in a residential facility.

Mr. CARTER. What about this using SSI funds for youngster?

Mr. SCHNORF. That youngster is multiply handicapped, physically handicapped and mentally retarded.

Mr. CARTER. I see.

Mr. SCHNORF. We are also representing some of the kinds of things that some of the earlier presenters spoke to, special education, placement appeals. For instance, in one school district in Southern Illinois, a family has successfully pursued a special education placement appeal, and has obtained from the school board a satisfactory placement in a class, but the school district refused to provide transportation for the child which rendered the earlier decision rather moot, and we successfully represented the mother in an appeal of that decision and obtained transportation for the child between home and the class the child had been approved for.

Concerning the type of issue that Ms. Bebee raised earlier regarding institutional advocacy, in our system a full-time advocate employed by us and independent of the State mental health agency will be assigned to each of the 12 State institutions, with a large number of DD residents, so we will have a full-time staff advocate in each of those institutions representing the interest and welfare available to the residents and their families to seek assistance from when problems of potential denial or abridgement of rights might occur.

That is a little background on where we are at in Illinois right now. We have carefully reviewed House Resolution 11764, and endorse it, including the proposed legislation's recommended continuation of the current definition of developmental disabilities. However, regarding the report that has been issued as called for under 94–103, of the two definitions recommended in the report, if those are the choices, we strongly endorse and recommend the minority report.

I have two specific concerns I would like to raise for the committee's consideration concerning 11764. One, if it is the sponsor's, and yours, Dr. Carter's, intent to provide additional funds for the protection and advocacy systems, and I believe that it is, as reflected in the recommended authorization for protection and advocacy included in the bill, then I urge the committee, as Ethan did earlier, to carefully review the potential negative result that might accrue to some protection and advocacy systems that are receiving substantial funding from their State DD planning councils.

We in Illinois for instance are receiving $200,000 for fiscal year 1978 for protection and advocacy from our state DD council. The recommended authorization level for fiscal year 1979 in the proposed bill might result in an increase in the Federal protection and advocacy funding to Illinois of even slightly in excess of $200,000, but that would be the approximate increase, we believe, based on the formula. If the bill is adopted as currently written, with P. & A. not included as one of four national priorities, we would lose our ability to receive funding from the State DD planning council, and the net result would be little, if any, increase in funding for P. & A. services in Illinois.

We would gain perhaps $200,000 from the formula, but lose $200,000 from the DD council, and we think that would probably not reflect the intent of the sponsor of the legislation. The same situation could hold true in any State where the DD council has made a substantial commitment to funding the P. & A. system.

As Ethan pointed out, nationally approximately 35 of the DD councils are committing some funding to P. & A. systems. I request that the committee look at various options for dealing with this possible eventuality, including something similar to a hold harmless clause that would permit DD councils to continue to fund P. & A. systems if they have done so in the past, or including D. & A. as a national priority eligible for funding by DD councils, regardless of what other priorities are selected and separate from the question of level of appropriations to State DD councils.

I am sure there are other options available to deal with the concern. I would, however, hate to see Illinois or any other State that has made a substantial commitment to protection and advocacy services penalized in the face of the obvious intent of the bill and the sponsor to increase funding for P. & A. systems.

Second, I would like to request that the committee consider incorporating into the bill language that would allow P. & A. formula funds under the act to be used as a match for other Federal funds, including title 20 of the Social Security Act. State DD council funds and other potential—I think there could be a variety of ones where a variety of Federal funding sources, where it wil lbe greatly advantageous to allow Federal P. & A. formula funds to be used as match.

One of the problems that has prevented some States from using DD council funds has been the unavailability of the local match, even though they are receiving the minimum of $20,000 under P. & A., it cannot be used to match the potential even small amounts of funds that they have received from the State planning councils.

I also from my own perspective personally, insofar as Illinois is concerned, would like to offer my thought. I question the priority decision that has been suggested in the bill. I have seen too many things happen in Illinois that over the past 7 years that have been beneficial, that could not have happened through the DD council, if these four national priorities had been in effect. I see things that we are looking at moving into right now. As an example, we are looking at a joint project with our DD council to put together an intensive seminar in Illinois for key leaders and decisionmakers in the legislature and the administration on the potential implications of recent court decisions on the future of institutional services, that might or might not be able to be snuck in under the rubric of community residential alternatives, but I would hate to foresee a situation where positive things could be done for relatively minimal amounts of money, in this case perhaps $3,000 or $4,000 that might be precluded by the perhaps—I don't want to say arbitrary, because I know it has been well thought out, but the perhaps unfortunate delineation of four narrow priorities for expenditure of DD council funds.

Thank you very much for the opportunity to speak to you.

Mr. CARTER. Thank you for a very good statement. Are there any protection and advocacy activities which are common to many States and which could be carried out better at the Federal level?

Mr. ROSSMAN. I might speak to that from an example. I think perhaps the answer is no.

Mr. CARTER. That is what I expected.

Mr. ROSSMAN. Let me share a fact situation with you we have recently encountered, which may give you a good example. An individual was referred to us by a State representative who had experienced employment discrimination on the basis of his having epilepsy. When I received the materials on this case, the first thing I did was try to find out why various places which he had been referred to did not help him.

First he had gone to the local epilepsy foundation. They were able to identify that he had reasonable cause to believe he had been discriminated against, and made a few phone calls, and found out that indeed they did discharge him because of his epilepsy, but really it ended there. There was nothing they could do. He was employed by the county in a social services program as a social worker, which was funded under a CETA grant, so they recommended he contact the contract compliance board of the Department of Labor in Atlanta, and he did that.

The Department of Labor determined that since CETA is a grant program and not a contract program, which is a 504 discrimination matter and not a 503 discrimination matter, they referred him to the Office of Civil Rights. The Office of Civil Rights in July 1977, accepted his case and had it on file, and I called them and said, what have you done about this. They said, absolutely nothing. They had not made the first phone call, the first inquiry, or written the first letter. Why? Because we are under an extreme backlog, handling not 504 discrimination cases, but race and sex discrimination cases, which they have been building up over the last several years, and in fact the office in Atlanta is not handling any 504 discrimination cases.

He was then referred to a State agency which was supposed to be able to handle employment discrimination cases, and they exercised their option to refer it to the protection and advocacy agency, and thereupon we got the case. Like Ms. Bebee indicated to you already, we have no more remedies than any private attorney, than any of our clients brings to us. We have no enforcement powers or investigatory powers of any kind. All we have is whatever cause of action the individual would have, and we generally deal with it ourselves or refer it, as I mentioned, to a local legal service program. We have referred it to a local legal service program.

The Catch-22 in this whole scenario is that as long as the Office of Civil Rights in Atlanta holds onto that complaint, the Federal courts probably will not even allow the case to survive, and will throw it out for failure to exhaust administrative remedies. So, all I am suggesting is, we really don't need any more Federal administrative remedies.

Mr. CARTER. Thank you.

Mr. SCHNORF. Dr. Carter?

Mr. CARTER. Excuse me. I would like to ask you what happened when you took over the case? Did you pursue it successfully?

Mr. ROSSMAN. We have just gotten it, and we put it in the hands of the local legal services program.

Mr. CARTER. All right.

Mr. SCHNORF. I can give a similar example, I think, that will indicate that sometimes even the Federal mechanism is counterproductive. In the case of Illinois, our fair employment practices commission has virtually this same situation. Because they received funding federally to pursue civil rights violations, sexual and racial discrimination issues get a priority. They have only probably successfully completed action on about 25 percent of the cases that have been referred to them since their inception. The other 75 percent are backlogs of 1½ years, but because of their priority to race and sex discrimination cases, they have completed action on zero percent of the complaints for discrimination because of handicaps which have been referred to them.

They received approximately 500 such complaints in the last 2 years, and have issued no rulings in 3 years on a case involving handicaps.

Mr. CARTER. I take it that you think P. & A. should be uniquely a State and local function.

Mr. ROSSMAN. Dr. Carter, if I may, there is one possible way of changing the existing legislation to perhaps make it more effective, and that would be for Congress to say that we have gone beyond the finding stages in the developmental disabilities bill of rights, and create enforceable rights, and perhaps couple that with a private right of action which attorneys might even be able to receive fees, and that would astronomically increase the effectiveness of our job.

Mr. SCHNORF. [Nods affirmatively.]

Ms. BEBEE. [Nods affirmatively.]

Mr. CARTER. Well, I certainly want you to keep it in State hands. I think it is a State and local function. Could you, Mr. Schnorf, submit those examples for the record so that the committee can consider them as we review the priorities?

Mr. SCHNORF. Yes, sir.

Mr. CARTER. I have one other question I would like to ask you gentlemen. Suppose that we have an orphan mental retardate who was left a sum of money. Would it be left up to the court to appoint a guardian for her?

Mr. ROSSMAN. That would be correct.

Mr. CARTER. You would not come in as an advocate in her case unless—you were called in, I guess.

Mr. ROSSMAN. No; in the State of Florida, at least, a public defender could be appointed to represent the interests, I believe.

Mr. Schnorf. It would be technically possible. The court might appoint an attorney from the protection and advocacy system as guardian at litem, during the time the hearing was—

Mr. Carter. This causes a great deal of worry for families who have only one child, who happens to be retarded. They worry about that child after they are gone. That is quite a problem.

Mr. Ellis. Dr. Carter, in New Jersey, we are currently reviewing the guardianship statutes, which are, according to our attorneys, very antique, and primarily designed to deal with property issues rather than other decisions that may be within the capability of the individual to make even though his intellectual functioning may be somewhat limited. Issues, for example, of whether or not an individual has the right to determine whether he wants to live in the community versus in the institution are, we take it, in some cases decisions they should be able to make, and we should not refer them to their guardian.

There are sometimes conflicts between the guardian wishes on the capabilities of the individual, and we have found a great need to review those statutes, on at least two issues that have recently come to us contesting those in the courts, so I think this is an issue we have to look into further.

Mr. Carter. I think that their rights certainly should be protected.

Thank you so much for your testimony. It has been very helpful.

Dr. Hugo Finarelli? Doctor, if you will highlight your statement, it will be greatly appreciated.

STATEMENT OF HUGO FINARELLI, JR., Ph. D., GOVERNMENT STUDIES AND SYSTEMS

Dr. Finarelli. Thank you, Dr. Carter.

I am very happy to have the opportunity today to describe the results of a study carried out by Government Studies and Systems on behalf of the Developmental Disabilities Office, the Office of Human Development. Our project had two primary goals: first, to design a set of model standards for evaluating the quality of services and programs to persons with developmental disabilities; and second, to devise a quality assurance mechanism which States could use to implement those standards.

The legislative mandate for the study was section 204 of the Developmentally Disabled Assistance and Bill of Rights Act. The language of section 204 suggests two prime motives for the study. First, there was apparent concern over the effectiveness of existing standards and quality assurance mechanisms. Second, there was a growing awareness of the need for outcome standards which directly State expectations regarding the developmental progress and the overall well-being of persons with developmental disabilities.

To date, most quality assurance efforts in developmental disabilities, as in other human services fields, have relied almost exclusively on input and process standards. Input standards specify organizational, administrative, and physical requirements that service providers must satisfy. Process standards describe the manner in which services should be delivered. The warrant for such standards is the belief that compliance with input and process requirements will contribute to or result in better outcomes for the persons receiving services.

Unfortunately, studies to determine whether or not this is true, whether compliance with input and process does result in better outcomes, have been infrequent and inconclusive. In fact, it has been widely contended that many of the standards currently promulgated by regulatory agencies and professional organizations are of doubtful validity, being neither necessary for quality nor predictive of desirable outcomes.

A second concern regarding standards in current use is simply their recent proliferation. At present, there are so many standards, from so many sources, that service providers are likely to find themselves subject to conflicting requirements, or are likely to face inconsistencies in the interpretation and use of similar standards issued by different jurisdictions.

Our first major project task, therefore, was to collect and classify hundreds of standards currently in use, to eliminate duplicates among them, and then appraise the remainder, to determine which were valid, reliable, and practical for use in quality assurance. On the basis of this extensive review, we were able to develop a set of input and process standards which we feel are nearly free of the defects found to be so common among existing standards.

The legislation clearly required, however, that the model standards go well beyond the traditional input and process requirements. In section 111 of the act, it is stated that services, treatment, and habilitation must be designed to "maximize the developmental potential" of persons with developmental disabilities. In turn, section 204 requires that the standards be "based upon performance criteria for measuring the developmental progress of persons with developmental disabilities." Therefore, a second major project task was to find a reliable set of measures of the developmental progress and overall well-being of persons with developmental disabilities.

The use of outcome measurement in quality assurance in human services is so rare, however, that the feasibility of this outcome-based approach was not known at the outset of the study. Therefore, we undertook a critical review of the state of the art of behavioral assessment in developmental disabilities and of outcome-based quality assurance in other human service fields. We concluded that outcome measurement is, in fact, feasible, and that outcome standards should play a significant role in quality assurance.

Finally, our project required us to design a model quality assurance mechanism which States could use to implement the proposed standards. By this we mean a set of administrative procedures which States could use to encourage, assist, or require service providers to maintain certain levels of quality as specified in the underlying standards.

Our methods, findings, and recommendations with respect to both standards and quality assurance mechanisms are described in detail in a series of reports prepared for the Developmental Disabilities Office. All of them are available for your examination. My purpose in the next few minutes, therefore, is to simply further highlight the results of our study.

As I mentioned before, our first major task was to review and evaluate existing standards. In order that this evaluation be objective, GSS staff and a group of experts in the field of developmental disabilities devised a series of precise judgment scales addressing such issues as the reliability of a given standard, the practicality of its use, and its susceptibility to action by the service delivery system.

The most important issue, however, was validity, whether or not the standard was judged to be a valid indicator of one of the three most desired outcomes: increased skill levels or the achievement of adaptive behaviors on the part of persons receiving services; more normalized patterns of daily living; and the protection of individual rights, including protection from neglect and abuse.

Nine experts in the field of developmental disabilities used this detailed evaluation protocol under the supervision of GSS staff to individually appraise several hundred of the standards in current use. The ratings of the experts led us to the conclusion that while the vast majority of existing standards express worthwhile sentiments and describe useful practices, they are nonetheless beset by recurring defects which render them of limited use in quality assurance.

These defects—lack of measurability, lack of reliability, lack of relevance, lack of objectivity, and in some cases lack of sensitivity to current concepts of human services delivery—render many of the existing standards ambiguous, obscure, or simply inappropriate.

Our next project task, then, was to develop a set of model input and process standards which maintained the best features of the existing standards, but eliminated these fundamental weaknesses. We feel that we were able to do this, that we were able to design a set of input and process standards which are valid, comprehensive and reliable for use.

Despite the fact that they are comprehensive, our model standards are relatively short in length. Most notably, there are no standards with respect to staffing levels, staff qualifications or credentials, or methods of service delivery, all common concerns in existing bodies of standards. Quite simply, we found that there is no consistent warrant, either professional consensus or empirical justification, for such standards. In fact, it is widely held that these standards tend to encourage overprofessionalization, overprotection, and other excesses that work against the best interests of persons with developmental disabilities.

On the other hand, our standards are quite detailed in some areas that we think are critical to the desired outcomes. For example, we specify in detail the minimum contents of individual habilitation plans, the core of individualized service delivery, and we specify at great length administrative procedures for the development of such plans. We also recommend numerous standards regulating living environments and other settings for service delivery, and prohibiting practices which we feel most restrict or deny the rights and dignity of persons with developmental disabilities.

In writing input and process standards, we have therefore had to walk a middle ground between the extremes overprotection and underattention. We had to balance the interests of those who need close supervision and protection, and those who need greater independence and freedom of movement. We think we have found that middle ground.

Our approach to the design of model outcome standards had to be somewhat different. As I mentioned earlier, our review of the literature in health, education, and rehabilitation services indicated that outcome measurement was rarely used for quality assurance, and that outcome standards are virtually nonexistent. Thus, most quality assurance in health and other human services falls at present in the category of "peer review," which is a congenial way of saying that colleagues and associates, members of the same professional organizations, appraise one another's work. More often than not, vaguely worded input and process standards, which do little to inhibit the intuitive conclusions of the appraisers, are used in these transactions. Our study of the feasibility of outcome standards demonstrated, however, that the absence of outcome standards is not due to any defect in the concept. Rather, we judge that it is due mainly to a small set of technical problems, all of which are solvable, and a long list of provider objections, most of which are groundless. We concluded, therefore, that there is no formal barrier to the use of outcome standards for quality assurance of programs and services for persons with developmental disabilities, provided technically competent approaches are used.

Specifically, we recommend outcome standards in two categories, developmental growth and normalization of living experiences. Developmental growth is measured by any of the scores of tested behavioral assessment scales and instruments currently in use. Of tive and self-help/independent living skills.
particular concern are motor, cognitive, social, affective, communica-

Our model standards also include two sets of normalization measures. The first set characterizes the degree to which persons are integrated into society at large by measuring the degree to which their social and physical environments are as normal as possible. The second set is used to compare the use of time by persons in supervised living situations with the use of time by persons of the same age and sex in the general population.

The problem with using outcome standards, of course, is the current lack of norms or expectations with respect to outcome measures, which makes it very difficult to estimate how much progress or change persons receiving services should experience over a given period of time. But our report does suggest several approaches for creating such standards, including the use of time series analyses, goal attainment approaches and comparison analyses.

In summary, we feel that the problem of setting outcome standards is solvable in a number of practical and understandable ways, and thus we recommend that States use outcome standards in conjunction with a concise set of input and process standards in their quality assurance efforts.

What, then, are the implications of our study?

To begin with, our recommendations regarding model standards and quality assurance mechanisms have been well received by State administrators and by service providers, as well as by the Developmental Disabilities Office. In some instances, organizations have taken steps to implement the recommendations on their own initiative. However, in a recent end-of-the-project workshop there was clear support for more formal follow-up activities.

The two key recommendations were the following: first, that the developmental disabilities office sponsor a project to provide technical assistance to up to five states that volunteer to field test the model standards. We see the field test as a key step in refining the standards further, in operationalizing the quality assurance mechanism, and in identifying and resolving any issues which arise during implementation.

Second, it was suggested that active support of field test activities be sought from other Federal agencies and programs that provide or fund services to persons with developmental disabilities, in the hope that early coordination among these agencies would eventually facilitate the consolidation of the many overlapping review processes to which service providers are now subject.

Thank you.

[Testimony resumes on page 487.]

[Dr. Fir:arelli's prepared statement follows:]

GOVERNMENT STUDIES & SYSTEMS

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A Summary of A Study
to Develop Model Standards
and Quality Assurance Mechanisms
for Services and Programs
for Persons with Developmental Disabilities

Testimony of
Hugo J. Finarelli, Jr., Ph.D.
Government Studies & Systems, Inc.

Presented at Hearings
of the Subcommittee on Health and the Environment
of the House Committee on
Interstate and Foreign Commerce

April 5, 1978

INTRODUCTION

Mr. Chairman and members of the Subcommittee, I am pleased to have the opportunity today to describe the results of a study carried out by Government Studies & Systems on behalf of the Developmental Disabilities Office, Office of Human Development. Our project had two primary goals:

(1) to develop a set of model standards for appraising the quality of services and programs for persons with developmental disabilities; and

(2) to devise a model quality assurance mechanism which States could use to implement the proposed standards.

The legislative mandate for our project was Section 204 of the Developmentally Disabled Assistance and Bill of Rights Act. The language of Section 204 suggests two prime motives for the study. First, there was an apparent concern about the effectiveness of existing standards and quality assurance mechanisms. Second, there was a growing awareness of the need for outcome standards that directly address both the developmental growth and the overall well-being of persons with developmental disabilities.

To date, most quality assurance efforts in the field of developmental disabilities, as in other human service fields, have relied almost exclusively on input and process standards. Input standards set forth organizational, administrative and physical requirements to be satisfied by service providers. Process standards describe the manner in which services should be delivered. The warrant for such standards is the belief that adherence by service providers to input and process requirements contributes to desirable outcomes for the persons receiving services.

Unfortunately, studies to determine whether compliance with input and process standards results in better outcomes have been both infrequent and inconclusive. In fact, it has been increasingly contended that many of the standards currently promulgated by regulatory agencies or professional organizations are of questionable validity, there being little evidence in most cases that existing standards are either essential to quality services or predictive of desirable outcomes.

A second concern regarding standards in current use is simply their recent proliferation. At present, there are so many standards, from so many sources, that service providers are likely to find themselves subject to conflicting requirements, or are likely to face inconsistencies in the interpretation and use of similar standards issued by different, and perhaps overlapping, jurisdictions.

Our first major task, therefore, was to collect and classify hundreds of the most widely used standards, eliminate duplicates, then appraise the remainder to determine which were valid, reliable and practical for use in quality assurance.

On the basis of that extensive review, we later developed a set of model input and process standards nearly free of the defects we found in existing standards.

The legislation clearly required, however, that the model standards go beyond the traditional input and process requirements. In Section 111 of the Act, it is stated that treatment, services and habilitation should be designed to "maximize the developmental potential" of the person. In turn, Section 204 requires that the recommended standards be "based upon performance criteria for measuring and evaluating the developmental progress of persons with developmental disabilities." Thus, a second major project task was to select reliable measures of the developmental progress and the overall well-being of persons with developmental disabilities, and then to design model outcome standards around these measures.

The use of outcome standards for human services quality assurance is so rare, however, that the feasibility of this outcome-based approach was unknown at the outset of the study. A critical review of the state-of-the-art of outcome-based quality assurance in other human services, and of behavioral assessment in the field of developmental disabilities, was therefore undertaken. Our conclusion was that outcome measurement is, in fact, feasible, and that outcome standards should play a significant role in quality assurance of services and programs for persons with developmental disabilities. Outcome standards for use in conjunction with the model input and process standards were thus also developed.

Finally, our project required us to design a model quality assurance mechanism. By this we mean a set of administrative procedures which will enable States to require, encourage or assist service providers to maintain (or at least to take steps toward achieving) certain levels of quality as expressed in a set of pre-established standards. Our concern here was to design a mechanism that would be effective, efficient and equitible when used with the model standards.

Our methods, our findings and our recommendations with respect to both standards and quality assurance mechanisms are described in considerable detail in a series of reports prepared for the Developmental Disabilities Office. All are available for your examination. Therefore, my purpose in the next few minutes is simply to further highlight the key findings and recommendations resulting from our study.

REVIEW AND EVALUATION OF EXISTING STANDARDS

In order to obtain an objective evaluation of existing standards, GSS staff and a group of experts in the field of developmental disabilities devised several precise judgment scales, addressing such issues as reliability, practicality of use, and susceptability to action, among others. The most important issue, however, was validity - whether or not the standard in question was a valid predictor of one or more of the three most desired outcomes: increased skill levels or the achievement of adaptive behaviors by the individual(s) receiving services; more normalized patterns of daily living; and enhancement of individuals' basic human rights, including protection from neglect and abuse.

Nine experts in the field of developmental disabilities - state program administrators, direct service providers, persons on the staffs of University Affiliated Facilities and others - used this detailed evaluation protocol under the supervision of GSS staff to individually appraise each of several hundred standards culled from the literature. The experts' ratings led us to the conclusion that while the vast majority of existing standards express worthwhile sentiments and recommend useful practices, they are nonetheless beset by recurring defects that limit their usefulness in quality assurance activities. These defects - lack of measurability, lack of relevance, lack of objectivity and lack of sensitivity to contemporary concepts of human services - generally render existing standards ambiguous, obscure or simply inappropriate.

MODEL INPUT AND PROCESS STANDARDS

Our next task, then, was to design a set of input and process standards which incorporated the best features of existing standards, but which also allowed for the adaptation of those existing standards judged valid but unreliable for quality assurance. New standards were also created where none existed. The result is a set of standards that, as far as we can now tell, is comprehensive, valid and technically reliable.

Despite its comprehensiveness, our list of model standards is short. Most notably, there are no standards with respect to staffing levels (ratios of staff to population served), staff qualifications or credentials, or methods for service delivery. We have found, quite simply, that there is no consistent warrant - either empirical justification or professional consensus - for such standards. Rather, there is widespread belief that such standards tend to foster overprofessionalization, overprotectiveness, and other excesses that can sometimes work against the best interests of persons with developmental disabilities.

On the other hand, our standards are quite detailed in areas that, as we see it, are directly predictive of desired outcomes. In particular, we have specified in detail the minimum contents of, and addressed at length administrative procedures for the preparation of, Individual Habilitation Plans - the core of individualized service delivery. We have also proposed numerous standards regulating living environments and other settings for service delivery, and prohibiting practices that seem to most restrict or diminish the rights and dignity of persons with developmental disabilities.

In writing input and process standards, we have therefore had to walk between the extremes of overprotection and underprotection. We have had to balance between the interests of those who need close attention and supervision and those who need greater independence and freedom of movement. We think we have found a valid middle ground.

MODEL OUTCOME STANDARDS

Our review of outcome measurement in education, health, rehabilitation and other human services showed that outcome measures are rarely used in quality assurance. In turn, outcome standards are virtually non-existent. Thus, most quality assurance in health and human services consists of "peer review," a congenial way of saying that colleagues and associates, persons in the same professional organizations, appraise one another's work. More often than not, vaguely worded input and process standards, which do little to inhibit the the intuitive conclusions of the appraisers, are used in these transactions.

Our feasibility study demonstrated, however, that the absence of outcome standards is not attributable to any defect in the concept. Rather, we judged that their absence is due mainly to a small set of technical problems (all of which are solvable) and a long list of provider objections (most of which are groundless). We concluded, therefore, that there is no formal barrier to the use of outcome standards in appraising services for persons with developmental disabilities, provided technically competent approaches are used. (Technical errors and excesses aid the political resistance forces.) Specifically, we believe that outcome standards should be developed for both developmental growth and normalization of living experiences.

The first outcome category, developmental growth, is measured by any of the scores of tested behavioral assessment scales or instruments. Of particular concern are motor, cognitive, communicative, social, affective and self-help/ independent living skills.

Our model outcome standards also include two sets of normalization measures. The first set is used to characterize the degree to which persons are integrated into society-at-large by measuring the degree to which their physical and social environments are as normal as possible. The second set of measures is used to compare the use of time by persons in supervised living situations with the use of time by persons of the same age and sex in the general population.

The difficulty of using these measures as standards, of course, is that we do not yet have an adequate set of norms or expectations from which we can estimate how much progress or change an individual (receiving services) should experience in a given period. Our report contains several recommendations for creating standards, including the use of time series analyses, goal attainment approaches (keyed to objectives set forth in a person's Individual Habilitation Plan), comparison group analyses or comparative program analyses.

In summary, we are satisfied that the problem of setting outcome standards is solvable in any of several practical and understandable ways. We conclude, therefore, that States can and should use outcome standards in their quality assurance efforts.

QUALITY ASSURANCE MECHANISMS

Quality assurance mechanisms are diverse, and quality assurance organizations have varied purposes. At one extreme, there are those organizations that view their mission as educational. At the other extreme are those agencies that license and regulate, that have the authority to impose sanctions against poor quality.

Whichever approach is adopted - our preference is for a positive, service-enhancing approach with sanctions reserved for only the worst offenders - there are fundamental design issues that must be addressed and a minimum set of implementation activities for which administrative procedures must be developed. The quality assurance mechanism we have recommended presents a step-by-step approach for the design phase as well as the implementation phase. Procedures which a quality assurance agency could use to carry out a self-evaluation of the effectiveness, efficiency and equity of its quality assurance activities are also suggested.

IMPLICATIONS

The model standards and quality assurance mechanisms developed in this project have drawn many favorable responses from State agencies and providers, as well as from the Developmental Disabilities Office. In some instances, organizations have already taken steps to implement our recommendations on their own initiative.

Nevertheless, a recent end-of-the-project workshop generated clear support for more formal follow-up activities. Two key recommendations were the following:

1. that the Developmental Disabilities Office proceed without delay to sponsor a project to provide technical assistance to five States which volunteer to field-test the model standards and model quality assurance mechanisms; the field-test is seen as a key step in the further refinement of the model standards, the operationalization of the model quality assurance mechanism, and the identification and resolution of any implementation problems which may arise;
2. that active support of the field-test activities be sought from other Federal agencies and programs which provide or fund services to persons with developmental disabilities in the hope that early coordination among agencies would facilitate the eventual consolidation of the many overlapping review processes to which service providers are now subject.

I shall be happy to answer any questions.

Mr. Rogers. Thank you very much. Your testimony was interesting, as we have had a lot of discussion about the outcome of standards. Dr. Carter?

Mr. Carter. Thank you, Mr. Chairman.

It is a very difficult task, I would think, to evaluate the standards of quality assurance in this particular area. I don't think you can project just what the outcome will be on different retardates. Certainly, we have had examples of people who had spastic conditions today who are certainly affected in no way mentally as far as was discernible. Measurement in this area is very difficult. We can see progress. How you specify it to a certain degree, a percentage, would be, it seems to me, very difficult.

Thank you, Mr. Chairman.

Mr. Rogers. What do you estimate the cost would be in evaluating someone on an outcome basis?

Dr. Finarelli. That we have not addressed yet. I can give you a couple of examples, however. The State that is doing the most in this regard at present is Minnesota. They have developed, at a cost, according to the project director, of approximately $350,000, which seems a modest cost for where they are so far, a behavioral assessment instrument called the MDPS, or the Minnesota developmental programing system, and they have administered that instrument as often as three times on an annual basis to the residents of all State institutions and many community residences in Minnesota, so that they are beginning to build up the longitudinal data base that is a prerequisite for setting outcome standards.

California, on the other hand, has spent an estimated $800,000 to $850,000 designing an evaluation system which includes outcome measures, JCAH-type facility surveys, and a cost accounting element. Their eventual goal is the ability to perform cost effectiveness analyses and to tie in licensing and quality assurance with evaluation. So there are two fairly wide estimates on the cost of developing an outcome-based system.

Mr. Rogers. If we were to authorize five demonstration projects, as you suggest, what should the funding be for those five projects, somewhere between $300,000 and $800,000 each?

Dr. Finarelli. I suppose it depends. Both Minnesota and California designed their own instrument for assessing an individual's skills and behaviors. If a State were going to do that, I would think half a million dollars would probably be a reasonable figure. On the other hand, if a State were willing to accept an instrument developed elsewhere, one could be talking of $100,000 to $200,000, perhaps.

Mr. Rogers. I see.

Dr. Finarelli. The proposal that technical assistance be provided was made on the assumption that States would assume responsibility for developing this kind of a system on their own, even without Federal encouragement or requirements, simply because they are spending so much money for developmentally disabled services that they should want to know themselves what the most effective programs were. So, at the time the recommendation was made, there was no discussion of Federal appropriations.

Mr. Rogers. Thank you so much. Have you any more questions?

Mr. Carter. No.

Mr. Rogers. We are grateful to you for being here. Thank you for giving us the results of your study.

Dr. Finarelli. You are welcome.

Mr. Rogers. That concludes our list of witnesses today. The committee stands adjourned.

[The following statement was received for the record:]

National Association of Private Residential Facilities for the Mentally Retarded

6269 Leesburg Pike, Suite B-5
Falls Church, Virginia 22044

Area Code 703 / 536-3311

STATEMENT PRESENTED
TO THE
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT
OF THE
HOUSE COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE
RELATIVE TO
H.R.11764 TO RENEW THE DEVELOPMENTAL DISABILITIES ACT

The National Association of Private Residential Facilities for the Mentally Retarded (NAPRFMR) is composed of over four hundred private programs which serve mentally retarded and other developmentally disabled individuals. Members range in size from foster care facilities serving one or two people to large, full-service programs serving a hundred or more.

The NAPRFMR would like to take this opportunity to thank Representatives Rogers and Carter for introducing H.R.11764 to provide continuing support for the only Federal program which specifically addresses the needs of America's most vulnerable citizens. Those people who are severely handicapped before they become adults are deprived in special ways and, as was pointed out in the testimony of Mr. Ethan Ellis from New Jersey, are not only unable to speak for themselves, but suffer from the inability of the rest of us to adequately represent their needs.

- Definition of Developmental Disabilities -

NAPRFMR Members who serve adults usually serve a few individuals who are intellectually impaired but who do not fit the definition of "developmentally disabled." These people have been seriously brain damaged in adult life. Their needs are, indeed, very much the same as people whose disability originates prior to age eighteen, as required under the current definition. Despite the similarity of need exhibited by such adults, the NAPRFMR recognizes the special needs of people who are disabled before the learning process is complete. Our Members favor the adoption of the definition developed in the majority report from Abt Associates. We feel that this functional approach without specific mention of any special segment of this population will result in greater assurances that all people who become seriously disabled during their youth will be served by the Developmental Disabilities program. We fear that a listing of specific disorders tends to eliminate some people who should rightfully be served.

- Prioritization of Services -

In its capacity as a member of the Consortium Concerned With the Developmentally Disabled (CCDD), the NAPRFMR has been concerned with the need to demonstrate the effectiveness of the Developmental Disabilities Act more clearly. It was with this in mind and in the belief that the priority areas of community living arrangements; nonvocational, social developmental services; individual client management services; and infant developmental services represent those areas in which developmentally disabled persons experience the greatest need for Federal assistance. It is our belief that other needs are more readily addressed by other Federally supported programs. We are strongly supportive of the prioritization of services presented in H.R.11764. We feel that although there is a need for ongoing review and revision of planning for this population, the major planning has been completed in the States and it is time to direct more attention to the delivery of services.

- Employment of Handicapped Individuals -

Our Members are most supportive of continuing requirements for affirmative action in the hiring and promoting of people who are handicapped.

- Protection and Advocacy Systems -

The NAPRFMR is encouraged by the progress that is being made in the development of Protection and Advocacy Systems within the States and endorses the increases in authorization to fund these programs.

- State Formula Grants -

We also support the authorization levels provided for the State Formula Grant program. The increase in minimum allocations for the States is particularly important. The current level of $150,000 provides for very little in the thirteen states that are currently at that level. Additional funding will be needed so that more support can be provided to fill the gaps in service delivery to this population.

- State Planning Council -

NAPRFMR also supports the revisions proposed for State Planning Councils. The revised composition would provide for greater consumer involvement which we feel will increase the likelihood that the Developmental Disabilities program will address the greatest needs in the field. We join the National Association for Retarded Citizens in requesting that serious consideration be given to adding the requirement that one of the representatives of mentally impaired, developmentally disabled individuals be a relative or guardian of a person who is institutionalized. We find that it is difficult for those who do not have close involvement with the special considerations in institutional placement to adequately address the issues. We believe that it is important for a person with such familiarity to be involved in each State Council.

* * *

The NAPRFMR would like to thank all members of the Subcommittee on Health and the Environment for their expressions of concern for this vulnerable population. We encourage your full support for H.R.11764 to assure that programs for people who are developmentally disabled will improve in their ability to serve those in need.

[Whereupon, at 4:10 p.m., the subcommittee was adjourned, subject to the call of the Chair.]

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